

**SOUTH TEES**  
**JSNA**

Joint Strategic Needs Assessment

*JUNE 2024*

**MISSION**

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*We will ensure everyone has their right to a dignified death realised.*

**GOAL**

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*We want to improve the identification of people who are approaching end of life and enable choice - relating to personalised and coordinated care.*

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# 1. Introduction

## 1.1 Mission led approach

The South Tees Health & Wellbeing Boards have agreed to a “mission-led” approach, structured across the lifecourse. Each mission is a response to a significant local challenge, one where innovation, working together and aligning resources has a big part to play in driving large-scale change. The Missions each have a set of ambitious goals that further articulate and explain the Mission.

The JSNA will provide the intelligence behind the Mission(s) – it will develop our collective understanding of the Mission(s); the issues behind and the broad contributing factors to the current outcomes experienced. We are working across the Tees Valley authorities to develop a process on that footprint that facilitates deeper engagement from the ICB.

The vision and aspirations under the lifecourse framework already exist following previous development sessions of the LiveWell Board. The lifecourse framework consists of three strategic aims – start well, live well and age well.

Vision	Empower the citizens of South Tees to live longer and healthier lives		
Aims	Start Well	Live Well	Age Well
<b>Aspiration</b>	<b>Children and Young People have the Best Start in Life</b> We want children and young people to grow up in a community that promotes safety, aspiration, resilience and healthy lifestyles	<b>People live healthier and longer lives</b> We want to improve the quality of life by providing opportunities and support so more people can choose and sustain a healthier lifestyle	<b>More people lead safe, independent lives</b> We want more people leading independent lives through integrated and sustainable support

## 1.2 Age well strategic aim

There are two missions within the age well strategic aim. **The first mission relates to promoting independence for older people and the second mission relates to ensuring everyone has their right to a dignified death realised and delivered upon.** The goal within the second mission, and the focus on this needs assessment focuses on ensuring everyone has their right to a dignified death realised.

Aims	Mission	Goal
<b>Age Well</b>	<b>We will promote independence for older people</b>	<b>We want to reduce the levels of loneliness and isolation in our communities and ensure our places promote healthy ageing</b>
		<b>We want to reduce the level of frailty to improve healthy ageing</b>
		<b>We want to ensure our communities are dementia friendly</b>
	<b>We will ensure everyone has their right to a dignified death realised</b>	<b>We want to improve the identification of people who are approaching end of life and enable choice - relating to personalised and coordinated care</b>

## 2. What is our mission and why do we need to achieve it?

### 2.1 We will ensure everyone has their right to a dignified death realised.

Death with dignity is an ethical concept that refers to the end-of-life process, avoiding suffering and maintaining control and autonomy. In general, it is usually treated as an extension of the concept of dignified life, in which people retain their dignity and freedom until the end of their existence<sup>1</sup>.

The concept of dying with dignity depends on the cultural background and includes interventions to facilitate the maximisation of physical, mental, social, emotional, spiritual, and existential comfort of patients at the end of their life. It is also defined as relaxation in tranquillity in suffering<sup>2</sup>.

Moreover, there are definitions referring to limited invasive interventions, examinations and treatments or death without fear in a safe environment, an environment where the patient does not feel loneliness, and death occurs in a quiet and private place. By allowing patients to die with dignity in the way they want, at the right place, and manner, we are respecting their right to autonomy and giving them back a choice in a situation that is already out of their control.

Although a dignified death can be natural and occur without any type of assistance, the concept is frequently associated with the right to die, as well as with the defence of the legalisation of practices such as voluntary euthanasia, physician-assisted suicide, terminal sedation or the refusal of medical assistance. According to its defenders, the possibility of this type of practices would be what would guarantee a dignified death, keeping free decisions until the last moment and avoiding an unnecessary agony.<sup>3</sup>

Assisted dying is illegal in England and Wales under section two of the Suicide Act 1961. Under this act, a person judged to have assisted the suicide or attempted suicide of another person is liable to imprisonment for up to 14 years.

Palliative care and assisted dying are two distinct approaches to end-of-life care that often need clarification. While both are concerned with providing comfort and support to individuals facing terminal illness or terminal conditions, they differ in their focus and goals. Palliative care is focused on providing comfort and symptom relief to patients and their families, while assisted dying involves the intentional ending of a patient's life. The discussion surrounding assisted dying is included in this literature to reflect a growing number of nations that are or have revised laws around assisted dying in certain circumstances, such as the Netherlands, Belgium, Canada, Australia, Switzerland and New Zealand, among others.

## 3. What is our goal and why do we need to achieve it?

### 3.1 We want to improve the identification of people who are approaching end of life and enable choice - relating to personalised and coordinated care

There is an urgent need to improve end of life care services to ensure that everyone, regardless of their circumstances, receives the best possible personalised care. This includes ensuring that people can die in the place of their choice. To do this, we need to understand the barriers people are facing from a diverse range of communities and take appropriate steps to make end of life care policy and practice as socially inclusive as possible and for all people to receive the appropriate support and care in their last stage of life.

The NHS Long Term Plan commits to improving personalised palliative and end of life care for people of all ages and to address health inequity. The Local Government Association and Association of Directors of Adult Social Services' guide emphasises the role of councils in this area (National Palliative and End of Life Care Partnership, 2021)

We need to work collaboratively with all providers including the Local Authorities, Integrated Care Board (ICB), primary and secondary care, and community organisations, to identify people early and enable appropriate conversations and care planning as early as possible, which will lead to higher quality of end-of-life care, as well as fewer unplanned hospital admissions with more people experiencing a good death, in a place where they choose to die.

### 3.2 End of Life Definition

People are approaching the end of life when they are likely to die within a year (NHS England). This includes people whose death is imminent and people with conditions that mean they are expected to die within 12 months as well as people who:

- have an advanced incurable illness, such as cancer, dementia or motor neurone disease.
- are generally frail and have co-existing conditions that mean they are expected to die within 12 months.
- have existing conditions if they are at risk of dying from a sudden crisis in their condition.
- have a life-threatening acute condition caused by a sudden catastrophic event, such as an accident or stroke.

The most recent data from Statista UK showed that In 2021, there were 667,479 deaths in the United Kingdom, compared with 689,629 in the previous year, which was the most deaths in a single year since 1918, when there were 715,000. Although the death rate in the UK fell from 10.4 deaths per 1,000 people in 2000 to 8.7 in 2011, it has increased in the intervening years, and reached a rate of 10.3 by 2020. Hospitals are the most common location of deaths in England and Wales, followed by homes, and care homes.<sup>4</sup>

Some people do die in their preferred place. Some people experience excellent care in hospitals, hospices, care homes and in their own homes; but the reality is that many do not. Many people also experience unnecessary pain and other symptoms and there are distressing reports of people not being treated with dignity and respect and some not dying in a place where they chose to die.

Although individuals may have different ideas about what would, for them, constitute a 'good death', for many this would involve:

- being treated as an individual, with dignity and respect;
- being without pain and other symptoms;
- being in familiar surroundings; and
- being in the company of close family and/or friends.

Studies have found that most people prefer to die at home surrounded by family and friends in their most comfortable and familiar spaces, where there is a peaceful atmosphere, and where they can experience dignity. For a long time, a focus has been on where people want to die rather than how, and place and preference are currently shaping services for people at end of life. The appropriateness of this, and the capacity of different care settings to deliver peoples' preferences and aspects associated with a good death (things like being free from pain, being surrounded by loved ones, and having dignity and respect) are the things that are important to them personally during their final days of life.

We want to ensure that people at the end of their life are supported to make decisions that allow them and their family or carers to be prepared for their death and that their care is well coordinated and planned so that they can die in the place and in the way that they have chosen.

### **3.3 What is end of life care?**

End of life care is support for people who are in the last months or last year of their life and should help people to live as well as possible until they die. People should be asked about their wishes and preferences as early as possible and have these taken into account to plan their care. Family, carers or other people who are important to the person should also be supported at this time.

Sudden death, terminal illness, organ failure, and frailty are the four most common types of illness trajectories found in end-of-life care. Evidence suggests that the need for services at the end of life to assist with essential activities of daily living is at least as great for older persons dying from organ failure and frailty as for those dying from a more traditional terminal condition such as cancer, and that the need is much greater for older persons dying from advanced dementia. Nonetheless, the absence of a predictable disability trajectory based on the condition leading to death for most decedents poses challenges for the proper allocation of resources to care for older persons at the end of life.<sup>5</sup>

End of life care encompasses care and support for a person's mental and emotional needs, physical comfort, spiritual needs, and practical tasks. Around half a million people die in England each year and with an ageing population, the annual number of deaths is estimated to increase. The COVID-19 pandemic has also led to an increase in the excess death rate. Effective end of life care improves the quality of life of the dying person and those important to them.

End of life care requires a system wide approach. A range of agencies are often involved at the end of a person's life. This will include different parts of the NHS, GPs, community services and hospitals, also care providers within the community or care homes, councils, hospices and voluntary sector organisations. There is also critical involvement from the individual and their family and friends. The pattern and scope of involvement will vary for every individual, but for people to have a 'good death' all these parts need to work together.<sup>6</sup>

End-of-life care, like contemporary health care as it currently exists, could partner with community efforts to provide support and care for death, dying, loss and practical caring. Families and palliative care, dementia care or bereavement care services for example, would not be alone in shouldering the responsibility for this kind of care.

### 3.4 What is Palliative Care?

Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of patients and their families who are facing problems associated with life limiting illness, usually progressive. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial, or spiritual. Palliative care also helps those receiving care, families and carers deal with emotional, spiritual or practical issues arising from the illness. People of all ages can benefit from palliative care and at all stages of their illness.

Although it can include end of life care, palliative care is much broader and can last for longer. Having palliative care needs doesn't necessarily mean that you're likely to die soon. Some people have palliative care needs for years; whereas end of life care offers treatment and support for people who are near the end of their life.

Specialist palliative care services add to the provision of palliative and end of life care, usually seeing people with more complex needs, and working collaboratively with primary and community services to help deliver palliative and end of life care. The 2019 EAPC Atlas of Palliative Care in Europe estimated that there are around 860 specialist palliative and end of life care services for adults in the UK, including home palliative care teams, inpatient hospices, and hospital palliative care support teams. (Marie Curie better end of life report 2022)

People's palliative and end of life care needs, and complexity of their needs, will fluctuate throughout their journey, and this means that a flexible model of care is required. No single provider can provide for all needs and people will require access to a wide variety of non-specialist palliative care delivered by primary, community, acute and urgent care services, as well as specialist-level palliative care services, to enable the system to provide personalised care to the person.

It is estimated that approximately 1% of patients within every general practice are likely to die within the next year and therefore should be identified within the register. Evidence has found that early identification of patients who are likely to die within the next 12 months enables well-coordinated, pro-active quality care, and allows healthcare professionals to focus on better meeting patient's needs.

For the GP Practice population across the Tees Valley, published QOF Palliative Care prevalence shows that the North East and North Cumbria have seen a gradual increase over time in the proportion of patients on the palliative care register. This increase could be due to an increase in palliative care patients based on increasing population estimates, as well as an improvement in the identification and coding of patients who are recognised as having palliative care needs.

Figure 1: published QOF palliative care prevalence in the Tees Valley footprint.

Published QOF Palliative Care prevalence:						
Area	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21
Tees Valley	0.51%	0.72%	0.69%	0.65%	0.76%	0.70%
Cumbria and North East	0.55%	0.54%	0.53%	0.54%	0.67%	0.64%

Table 4: Published QOF Palliative Care prevalence.

Source – Tees Valley PEOLC Strategy



Although there is an improvement year on year, there is still a way to go to achieve the required 1% level and ensuring we are identifying and therefore supporting all local patients with a palliative care need.

For the purpose of the Age Well strategic aim of the JSNA, the focus on this needs assessment will be on people aged over 65years.

## 4. Key data and drivers for change

### 4.1 Palliative Care Register

Data provided by North East Commissioning Support Unit (NECS) shows the number of patients on GP records that are recorded on a palliative care register by Primary Care Network (PCN). In South Tees as of June 2023, there were 1,661 patients on the palliative care record or 2.9% of the practice population aged 65 and over. This was similar to the Tees Valley rate of 2.8%. There is some variation across PCNs in South Tees with Holgate PCN higher at 4.2% of population and East Cleveland PCN lowest at 2%.

Figure 2: Palliative care register by Tees Valley PCN

LA	Primary Care Network	Patients (65+)	Palliative Care Register No.	Palliative Care Register %
Darlington	Darlington PCN	22,807	547	2.4%
Hartlepool	Hartlepool Health PCN	5,608	317	5.7%
	Hartlepool Network PCN	6,272	182	2.9%
	One Life Hartlepool PCN	6,681	170	2.5%
Stockton-on-Tees	Billingham & Norton PCN	10,726	371	3.5%
	Bytes PCN	10,341	246	2.4%
	North Stockton Network PCN	8,587	175	2.0%
Middlesbrough	Stockton PCN	9,428	217	2.3%
	Central Middlesbrough PCN	6,841	207	3.0%
	Greater Middlesbrough PCN	11,131	296	2.7%
Redcar & Cleveland	Holgate PCN	7,638	318	4.2%
	Eston PCN	8,891	235	2.6%
	Redcar Coastal PCN	12,997	396	3.0%
	The East Cleveland Group PCN	10,507	209	2.0%
	<b>SOUTH TEES</b>	<b>58,005</b>	<b>1,661</b>	<b>2.9%</b>
	<b>TEES VALLEY</b>	<b>138,455</b>	<b>3,886</b>	<b>2.8%</b>

Source – NECS business intelligence team

Figure: 3 below shows the prevalence of a selection of long-term conditions that account for much of the palliative care demand in adults, and prevalence generally increases with age. There is higher prevalence rate of these conditions particularly in Central Middlesbrough PCN and Eston PCN so assumptions can be made that these PCNs would have higher rates of patients on palliative care registers.

Figure 3: Risk factors for over 65s associated with greater need for palliative care by PCN

Risk Factors	Middlesbrough PCNs			Redcar & Cleveland PCNs			South Tees	Tees Valley
	Central M'Bro	Greater M'Bro	Holgate	Eston	Redcar Coastal	East Cleveland Group		
Heart Disease	15%	14%	14%	15%	14%	13%	14%	14%
Kidney Disease	14%	17%	10%	16%	15%	10%	14%	15%
Stroke	5%	5%	6%	5%	5%	5%	5%	5%
Cancer	13%	13%	13%	14%	14%	13%	13%	13%
Asthma	10%	9%	9%	8%	8%	8%	9%	9%
COPD	12%	12%	10%	12%	11%	9%	11%	10%
Diabetes	21%	20%	18%	22%	19%	17%	20%	18%
Dementia	5%	4%	4%	4%	5%	4%	4%	4%

Source - NECS business intelligence team

## 4.2 Place of Death

Monitoring who dies and where is important in delivering high quality palliative and end of life care. The Ambitions for Palliative and End of Life Care Framework figure 4 highlights that personal choice in place of care and death is fundamental to the lived experience of the dying and their families.

Data below shows the place of death for residents in South Tees for all ages and by age groups over 65s. For all ages both South Tees LA's are similar to England for deaths occurring in hospital and care homes. Both South Tees LA's have slightly higher rates of those dying at home and lower rates of those dying in a hospice.

Data by age group shows that for hospital deaths, a higher proportion of 65–74-year-olds are dying there in Middlesbrough compared to Redcar & Cleveland and England. For care home deaths, Redcar & Cleveland has a lower percentage of deaths for the 65–74-year-olds compared to England and higher rates in both LAs for 75-84 and 85+ year olds. For deaths at home, Redcar & Cleveland has a higher rate compared to England for 65–74-year-olds whilst Middlesbrough is lower. 75–84-year-old rate is relatively similar to England whilst the rate for those aged 85+ years old is lower in both LAs compared to England. Deaths in a hospice are lower across all age groups compared to England.

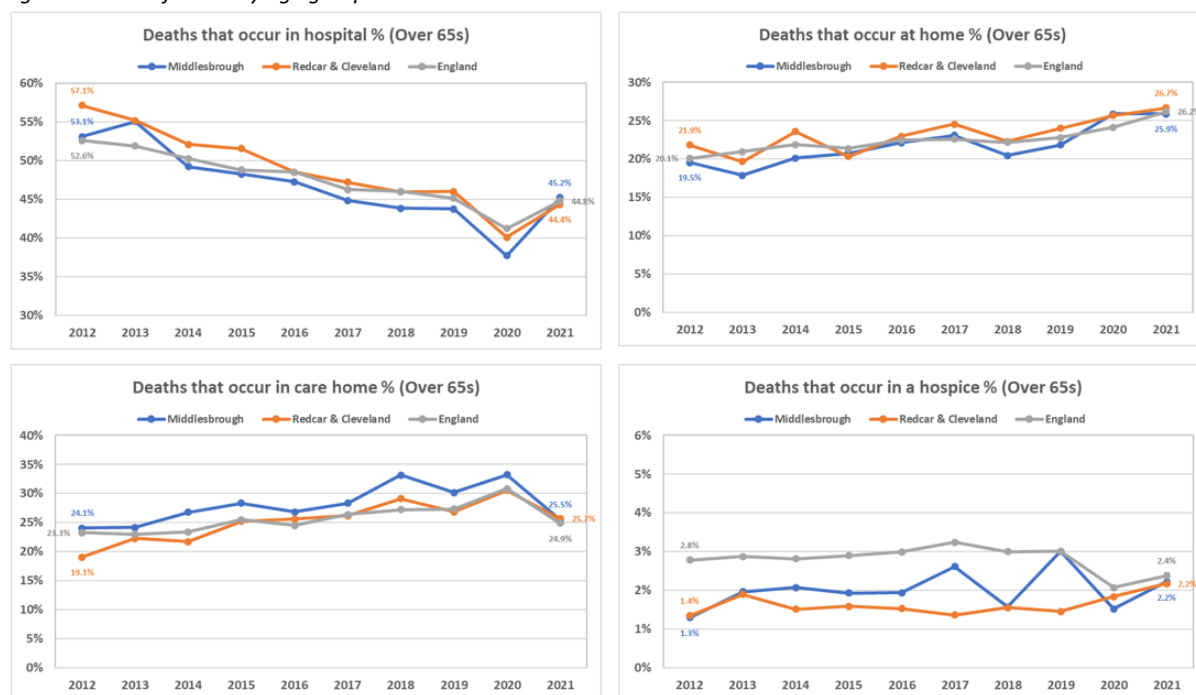
Figure 4: Place of death by age group

Place of Death	Age Group	Middlesbrough	Redcar & Cleveland	England
Hospital	65-74	55.4%	47.7%	48.6%
	75-84	44.7%	47.4%	47.5%
	85+	39.5%	39.7%	38.8%
	<b>All Ages</b>	<b>45.0%</b>	<b>44.3%</b>	<b>44.0%</b>
Care Home	65-74	8.0%	6.1%	7.7%
	75-84	21.2%	21.3%	17.3%
	85+	39.9%	40.9%	35.0%
	<b>All Ages</b>	<b>28.9%</b>	<b>28.7%</b>	<b>28.7%</b>
Home	65-74	31.7%	38.9%	34.5%
	75-84	31.6%	29.0%	28.9%
	85+	17.3%	17.6%	22.7%
	<b>All Ages</b>	<b>21.1%</b>	<b>21.9%</b>	<b>20.2%</b>
Hospice	65-74	3.8%	5.5%	6.7%
	75-84	1.5%	1.3%	4.6%
	85+	1.9%	1.0%	2.1%
	<b>All Ages</b>	<b>2.7%</b>	<b>2.4%</b>	<b>4.4%</b>
Other places	65-74	1.0%	1.8%	2.4%
	75-84	1.1%	1.0%	1.6%
	85+	1.3%	0.9%	1.3%
	<b>All Ages</b>	<b>2.4%</b>	<b>2.7%</b>	<b>2.7%</b>

Source – Fingertips, OHID

Trends in the location of deaths for both local authorities follow the national trend with a decrease in deaths occurring at hospital and an increase in deaths at home and care homes. In 2020 during the Covid-19 pandemic, the proportion of deaths that occurred at home increased and deaths in hospital reduced. This may reflect patient choice to die at home during the pandemic, when hospital and care home visiting was restricted. It could also indicate that people were deterred from seeking medical help or avoided being admitted to a care home due to concerns about catching Covid-19.

Figure 5: Place of death by age group



Source – Fingertips, OHID

## **Place of death - Hospital**

Although deaths that occur in hospital have decreased over time, the number of people who need palliative and end of life care is increasing and without a corresponding increase in palliative and end of life care at home, then by default, hospital admissions and hospital deaths will increase.<sup>7</sup>

Research has found that having a carer was the single most important factor associated with a person dying at home, whereas living alone or being unmarried increased the likelihood of a person dying in hospital.

Studies show that there is not enough support available in the community to care for people who are terminally ill and approaching the end of life. This includes a lack of investment in primary care, social care and community based palliative care services, including those delivered by the third sector. Often there are delays in care packages that can mean people cannot get home and die waiting in hospital..

Macmillan insight study in 2012 highlighted that (73%) of people with cancer would prefer to die at home, less than a third (29%) are able to do so and this meant that 36,000 cancer patients died in hospital when they would have preferred to die at home.

Acute unplanned admissions exponentially increase towards end of life, contributed to by failure to recognise someone as ill enough to die, medicalisation and some evidence around lack of choice and failure to plan.

The Lancet Commission on the value of death report, highlights that rebalancing is needed of the relationships and partnerships between people who are dying, families, communities, health and social care systems, and wider civic society<sup>8</sup>

Without concerted action to improve availability of basic community services at all times throughout the day and night, people approaching the end of life will be continue to be admitted to hospital unnecessarily and often against their wishes. However, if patients' conditions decline, they may need to be admitted to hospital if the home is not considered a suitable place of care and death, and offers benefits to patients, family carers, and staff.<sup>9</sup>

High quality out-of-hours care at home should be available for all who need it, despite some examples of excellent practice, we need to plan for the known future increase in palliative care needs, and address current challenges, so that the right community-based care is available at the right time, for everyone who needs it. Communication is paramount between the GP, patient and family with support from the nursing teams. This is crucial, not only for the individuals concerned and the people caring for them, but also to reduce strain on emergency departments and acute hospital beds, which often become the default place for care when support and care at home is not rapidly and reliably available. (Marie Curry 2022)

## **Place of death - Home**

When someone expresses a wish to die at home, it is often because they have a relative or friend who is available to be their carer. As a result, carers will often take on the vast majority of personal care responsibilities for someone who is approaching the end of life and wants to die at home.

Data shows that in South Tees only 21% of people over 65 died at home compared to 45% who died in Hospital. Although this is similar to the National average, studies are showing that a high percentage of people are not dying in their place of choice.

Across the UK, much palliative and end of life care at home is provided by primary and community services, including general practitioners, district nurses and community nursing teams, with support from allied health and social care practitioners.

District nurses provide evidence-based care and support to patients in their own homes. Predominantly providing diabetes care, general wound care (including pressure ulcer and leg ulcer management), administration of medications via a variety of routes, intra venous antibiotics palliative and end of life care, diagnostic testing and phlebotomy, catheter care and complex patient management<sup>10</sup>.

If we are to make deaths at home more achievable, we need to do more to ensure sufficient support for those paid carers who may be vital to sustaining the viability of care at home. Essential provision with rapid and reliable specialist clinical services that offer support for patients at home for extended periods of time is needed, such as hospice at home, Macmillan, and Marie Curie nursing services.

#### Case example Carer

“The GP felt it wasn't in his role or he wasn't able to refer mum to the specialist services, but once the district nurse had been, the referral was done. The consultant and a Macmillan nurse came out to see mum and put her on meds which helped significantly”.

“We need a more structured group of specialists working in the community, more Staff working closely together as a team, especially out of hours, evening and weekends and as a family it should be clear who to contact if you urgently need help and have confidence in the service”.

*Source - Tees Valley Adult Palliative and End of Life Care Strategy 2022-2027, North East North Cumbria Integrated Care Board*

Although funding is limited, it is possible that community-based care could be more affordable if it results in unwanted unavoidable hospital admissions, therefore funding should be invested into community end of life care provision as well as hospices and care homes and consideration should be given to improved care planning and communications to support people to remain at home or be supported in a community setting.

#### **Place of death - Hospice**

Hospices aim to feel more like a home than hospitals. They can provide individual care more suited to the person who is approaching end of life, in a gentler and calmer atmosphere than a hospital (NHS England)

The reason people die in a Hospice depends on many factors, primarily on the level of care a person needs and whether that care can be provided by family and friends at home. The objective of hospice care is to keep a person comfortable (such as by reducing their pain) but not treat their terminal disease.

Although there are limited beds in Hospice Care and these are usually taken up by complex cases, people do have a better experience of dying in a hospice compared to hospital. The National Bereavement Survey 2012 (VOICES) shows that over half of respondents whose loved one died at home (53%) or in a hospice (58%) rated the quality of care in the last three months of life as ‘outstanding’ or ‘excellent’. But the same figure for those who died in hospital was only a third (34%).

Deaths that occur in a Hospice increased in 2021 compared to 2022 for both Middlesbrough and Redcar and Cleveland for over 65s and this was similar to the UK National Average of deaths that

occurred in a Hospice. This increase could be due to the pandemic which led to major disruption to services right across health and social care, as well as a huge shift in where patients were dying, with more than 105,000 extra deaths at home in the UK over the first two years of the pandemic.

Data from the Teesside Hospice shows that in 2022-23 there were 126 patients admitted for end-of-life care; of these 74 died in the hospice and 52 were discharged either to their home, to a nursing home or to hospital. All patients who died in the hospice had identified their preferred place of death as Teesside Hospice.

With increasing age, older people become less likely to want to die at home, for a variety of reasons: most women outlive their partners and live alone; if people do have spouse carers, these spouses are usually of an older age and may have their own health problems and there is great concern about being a burden on family and being dependent on others, especially for 'intimate' needs such as toileting and bathing<sup>11</sup>. Many people may start off with a preference to die at home, but as their condition and circumstances change and the nearer to death they are, so can their place of preference.

It is important that preferred place of death is recorded and kept up-to-date as individual circumstances change.

### **Place of death - Care Homes**

Care homes include residential and nursing homes, run privately, by local authorities or by the NHS. They range from independent sheltered accommodation to full nursing homes.

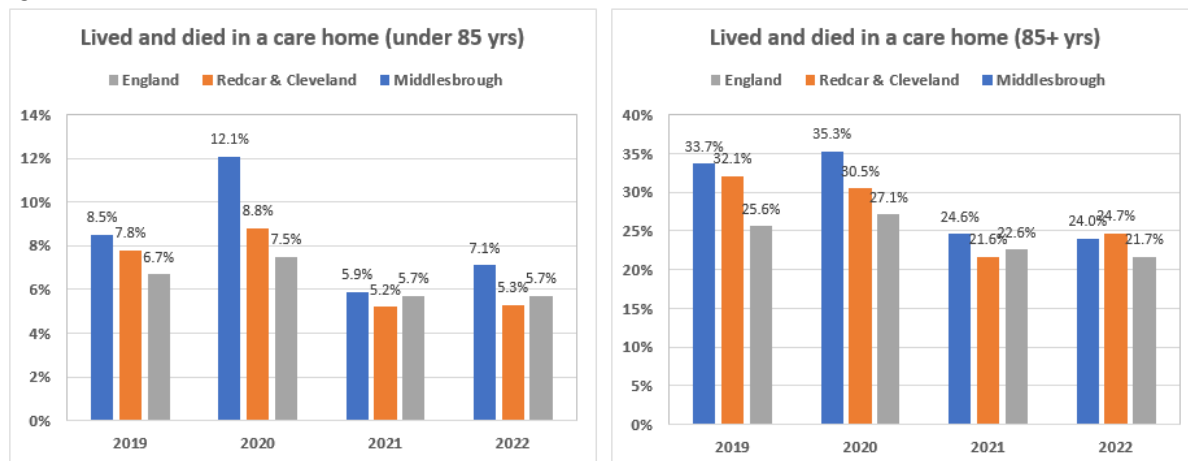
Many people enter a care home because they are no longer able to live independently in their own home. For these people the care home becomes their usual place of residence, and many would choose to stay there until they die. Others enter a care home for respite care, or for nursing care and rehabilitation, with a view to returning to independent living<sup>12</sup>

## **4.3 Care home deaths**

In 2021 in Middlesbrough, of all people who died in a care home, 41.8% (142 of 340) died with dementia and in Redcar and Cleveland, 45.8% (170 of 371) died with dementia compared to 47.4% in England. In Middlesbrough, of all people who died with dementia, 54.8% (142 of 259) died in a care home and in Redcar and Cleveland 61.8% (170 of 275) died in a care home, compared to 54.9% in England. The tables below provide a summary of the percentage of people who died by care home 'cared for' group present for 2 age groups (under 85 years and 85 years and older) for 2019 to 2022.

Figure 6: below shows the rate of persons who lived and died in a care home as a percentage of all deaths. In 2022, Middlesbrough has a higher rate whilst Redcar & Cleveland has a lower rate compared to England for those under 85 years. The Covid pandemic has a impact on the 2020 figure, where Middlesbrough had a significantly higher rate. For those aged 85 years and over the rates are much higher, and both Middlesbrough and Redcar & Cleveland have higher rates compared in England in 2022.

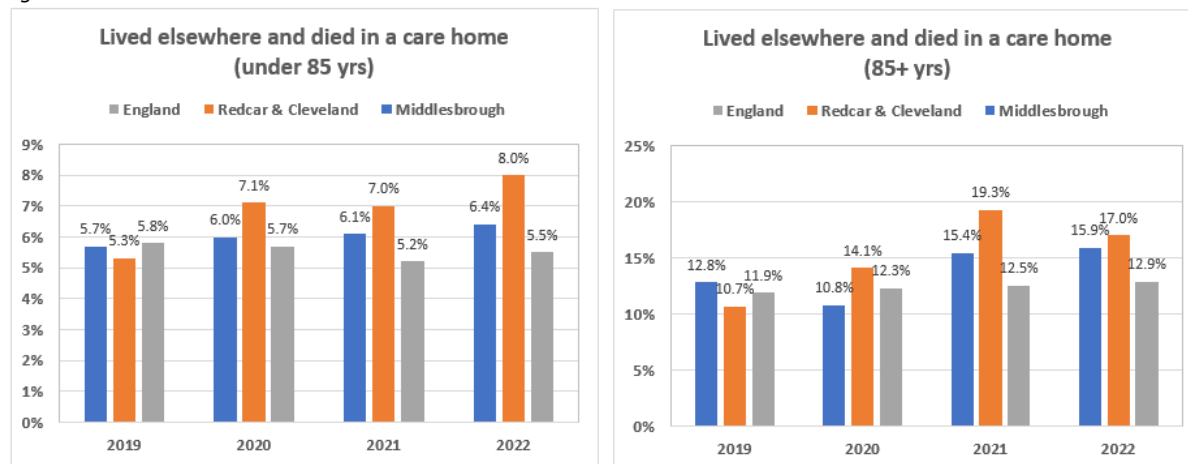
Figure 6: Persons who lived and died in a care home



Source – Fingertips, OHID

Figure 7 below shows the rate of persons who lived elsewhere and died in a care home. In 2022, Middlesbrough has a higher rate whilst Redcar & Cleveland has a significantly higher rate compared to England for those under 85 years. Redcar & Cleveland has been significantly higher compared to England since 2019 where the rate was lower compared to England. For those aged 85 years and over the rates show a similar picture.

Figure 7: Persons who lived elsewhere and died in a care home



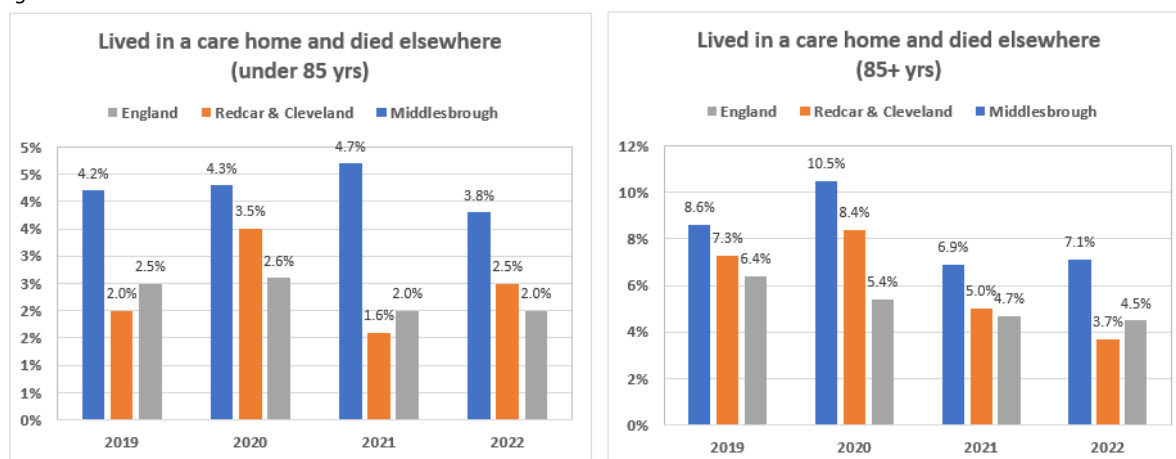
Source – Fingertips, OHID

Temporary admission to a care home may occur following discharge from hospital during a terminal illness, when someone needs short term support recuperating from an illness or for a trial period to decide whether they want to live permanently in a care home.

Figure 8 below shows the rate of persons who lived in a care home and died elsewhere. In 2022, and previous years Middlesbrough has a higher rate compared to England, whilst Redcar & Cleveland has a slightly higher rate for those under 85 years. For those aged 85 years and over the rates show a similar picture. Died elsewhere refers to possibly another private residence, a public place or not in a building.



Figure 8: Persons who lived in a care home and died elsewhere



Source – Fingertips, OHID

In terms of preferred place of death (PPOD) studies have shown that it is unknown what proportion of UK patients prefer to die at home. Home was majority preference, but only when missing data were excluded. There was also no known difference between preferences for home and the diagnosis of patients. The homogeneity of the perspectives of the general public or family caregivers correlates poorly with the heterogeneity of patient wishes for PPOD. Preferences may be contextualised by where participants are being cared for when they are asked their preferences. Ultimately, preferences for place of death appear to depend on who is asked the question; what, where, why and when they are asked; and how those without an answer were included.<sup>13</sup>

#### 4.4 Care homes rates

Figure 9 below shows the number of care home and nursing home beds in our two local authorities and the rate of permanent admissions to residential and nursing care homes. Our local rates of permanent admissions to care homes were the highest in England in 2021/22 for those aged 65+ and Middlesbrough has a very high rate of care home and nursing home beds per population. This means that many of our older population locally will not have the ability to die at home compared to older people nationally, as movement into care homes is happening at an earlier age and at greater rates.

Figure 9: Care home bed rates

Indicator	Period	Middlesbrough			Redcar & Cleveland			North East	England
		Count	Rate	Rank*	Count	Rate	Rank*	Rate	Rate
Permanent admissions to residential and nursing care homes per 100,000 aged 65+	2021/22	319	1,374	1st	335	1,071	2nd	739	539
Care home beds per 100 people 75+	2021	1,777	17.2	1st	1,348	9.3	75th	10.8	9.4
Nursing home beds per 100 people 75+	2021	845	8.2	2nd	549	3.8	111th	5.8	4.6

\*Rank of out 150 local authorities

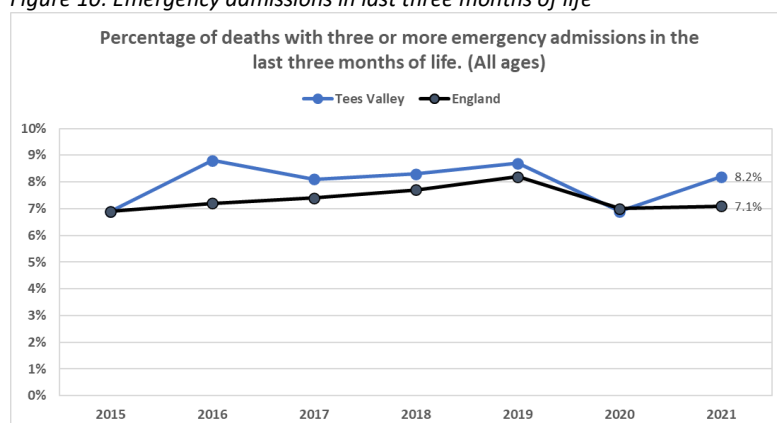
Source – Fingertips, OHID

## 4.5 Emergency admissions

Multiple emergency admissions at the end of life are disruptive and can impact on a person's quality of life. If this measure is high this could be linked to poor identification of people at risk of dying, poor planning and/or availability of services to support people in the community or poor communication, co-ordination and information sharing. Figure 10 below shows that in 2021 Tees Valley had a higher rate of deaths with 3 or more emergency admissions in the last 3 months of life at 8.2% compared to 7.1% in England.

In 2020 the data showed a reduction, which will have been affected by many factors, in particular the impact of the COVID-19 pandemic on admissions to hospital, changes in the way end of life care was delivered in the community and the increased number of people who died especially over the age of 75 years. Before 2020 the percentage of emergency admissions prior to death were increasing both in Tees Valley and England, suggesting rates will be higher again in 2022 once some of the effects of the Covid pandemic have passed.

Figure 10: Emergency admissions in last three months of life



Source – Fingertips, OHID

Local data provided by NECS business intelligence team provides a more up to date situation regarding patients with emergency admissions within 3 months of end of life. The data covers a 12 month period between October 2022 and September 2023. Figure 11 below shows that the Tees Valley has a slightly lower rate compared to the regional ICB, with 9.1% of patients with three or more emergency admissions prior to death. PCNs such as Holgate PCN and Redcar Coastal PCN have lower rates of single and multiple admissions prior to death and a small proportion who died in hospital. Eston PCN has a much higher proportion at 12.4% who had 3 admissions and also a greater proportion who died in hospital at 56%.

Figure 11: Emergency admissions in last three months of life

Area Type	Area Name	Propn of patients with EMG admissions in final 3 full calendar months of life		Died in hospital
		1+	3+	
ICB	North East & North Cumbria ICB	74%	9.6%	37%
Sub-ICB Area	Tees Valley	74%	9.1%	37%
Tees Valley Primary Care Network	Central Middlesbrough PCN	80%	7.9%	36%
	Greater Middlesbrough PCN	75%	7.1%	37%
	Holgate PCN	71%	7.0%	34%
	East Cleveland PCN	71%	7.6%	38%
	Eston PCN	80%	12.4%	56%
	Redcar Coastal PCN	72%	7.8%	34%

Source – NECS business intelligence team

In South Tees, just under 40% of patients who died between October 2022 and September 2023 were on a palliative care register. This is slightly higher than the Tees Valley and regional average. There are large variations between PCNs locally, with the highest rate on a palliative care register in Holgate PCN at 46.7% and the lowest in Eston PCN at 32.2%. Holgate PCN also had a higher rate of those who had 1 or more or 3 or more admissions prior to death who were on a palliative care register, with Eston PCN also showing the lowest rates.

Figure 12: Emergency admissions in last three months of life on palliative care register

Area Type	Area Name	Deceased patients			Deceased patients with 1+ admission in last three calendar months of life			Deceased patients with 3+ admission in last three calendar months of life		
		Total	Of which on PC register	Propn on PC register	Total	Of which on PC register	Propn on PC register	Total	Of which on PC register	Propn on PC register
ICB	North East & North Cumbria ICB	30,598	11,877	38.8%	22,509	13,980	62.1%	2,929	1,296	44.2%
Sub-ICB Area	Tees Valley	7,014	2,549	36.3%	5,193	3,069	59.1%	639	273	42.7%
CCG	South Tees	3,104	1,236	39.8%	2,304	1,413	61.3%	258	102	39.5%
Tees Valley Primary Care Network	Central Middlesbrough PCN	368	164	44.6%	294	194	66.0%	29	13	44.8%
	Greater Middlesbrough PCN	602	239	39.7%	450	249	55.3%	43	14	32.6%
	Holgate PCN	441	206	46.7%	311	246	79.1%	31	21	67.7%
	East Cleveland PCN	433	171	39.5%	306	177	57.8%	33	12	36.4%
	Eston PCN	516	166	32.2%	411	225	54.7%	64	14	21.9%
	Redcar Coastal PCN	744	290	39.0%	532	322	60.5%	58	28	48.3%

Source – NECS business intelligence team

Figure 13 below shows the top 10 most frequent causes of multiple emergency admissions prior to end of life. Pneumonia is the most common cause with 8.9% of all admissions, followed by COPD and bronchiectasis and Septicemia both with 6.4%. Patients on the palliative care register (compared to those dying who are not on the palliative care register) are more likely to have admissions for Pneumonia, septicemia and secondary malignancies and are less likely to have admission for COPD, COVID and renal failure.

Of admissions in the three months prior to death, 61% are via A&E (55% of those of patients on palliative care registers), 16% of admissions are via GPs (19% of those patients on palliative care registers) and 23% are recorded as other sources of emergency admission.

Figure 13: Admission causes for multiple admissions prior to death

Diagnosis group	Admissions (EMG)	Proportion
Pneumonia	233	8.9%
COPD & bronchiectasis	168	6.4%
Septicaemia; Shock	166	6.4%
Urinary tract infections	95	3.6%
Congestive heart failure; nonhypertensive	90	3.5%
Secondary malignancies	88	3.4%
Other connective tissue disease	63	2.4%
Acute bronchitis	61	2.3%
Cancer of bronchus; lung	56	2.1%
Fluid and electrolyte disorders	56	2.1%
Top 10 Total	1,086	41.7%
Total	2,605	100%

Source – NECS business intelligence team

Looking at admission in the final months of life for all patients and not just those with 3 or more admissions there are again significant differences within the ICB and within the Tees Valley sub-ICB area. Eston PCN had the highest rate per 100 deceased patients who had admissions in the last three months of life with a rate of 154 admissions (794 admissions for 516 deceased patients). Central

Middlesbrough PCN had the next highest rate with 121 per 100 patients and East Cleveland PCN was lowest with a rate of 102 per 100 patients. The most common reasons for emergency admissions in the Tees Valley in the final 3 months of life are for respiratory admissions, cardiovascular and cancer. This broadly reflects the pattern across North East and North Cumbria.

A report by PHE (March 2020) on emergency admissions identified that the percentage of people with 3 or more emergency admissions in the last 3 months of life was:-

- highest for people with an underlying cause of death of liver disease, COPD, and cancer
- highest in the London NHS region
- higher in urban areas than rural areas
- higher for males than females
- lower for White British than all other ethnic groups
- higher in females than males for those aged under 70
- higher in males than females for those aged 70 and older

Of the people with 3 or more emergency admissions in the last 3 months of life:

- more than a quarter had cancer as the underlying cause of death
- three-quarters spent at least 13 days in hospital
- most were aged 70 and older

The NHS adopted a key performance indicator 'The percentage of deaths with 3 or more emergency admissions in the last 3 months of life' to encourage improvement in the quality of end-of-life care. This was intended as a measure of end-of-life care services and not a direct measure of the quality of care at the individual level. It was actively monitored by Sustainable Transformation Partnerships (STPs) and the former clinical commissioning groups (CCGs) to investigate when this measure is high, which could indicate:<sup>14</sup>

- Poor identification of people at risk of death
- Poor planning and availability of services
- Poor communication, co-ordination, and information sharing.

Although preferences for care may change and many admissions are unavoidable, targeted actions need to be developed, that focus on a reduction in the number of emergency admissions for patients on the PEoL register and consideration should be given to improved care planning and communications to support people to remain at home and/or be supported in a community setting.

## 5. What are we already doing in relation to this goal?

A consultation workshop held in July 2023 at Inspire to Learn in Redcar and Cleveland, included over 40 professionals including ICB leads, NHS Clinical Leads and other representatives from Statutory and Voluntary Community Organisations, to share their expertise, knowledge, and experience in end-of-life care, with a focus on the below questions.

- What partnerships, programmes and projects are in place in relation to this goal and what is the focus of their work?
- What services (including commissioned services) are in place to address local needs in relation to this goal?
- What are older people’s experiences in relation to this goal?
- What are the key recommendations in relation to this goal?

Notes from the table discussions and further reflections are included in tables 1 and 2 below.

### 5.1 What partnerships, programmes and projects are in place in relation to this goal and what is the focus of their work?

Table 1 workshop notes – End of Life goal discussions

Workshop notes	Further information and reflections
Incorporating Core20plus5 approach (national NHS England approach to inform action to reduce healthcare inequalities at both national and system level)	Encourages working together as an integrated care system to understand and address health inequalities in end of life with a focus on population groups and clinical areas. See more information in 6.1 Inequalities in end-of-life care
End of life Training for care homes although inconstant. Department of Health End of Life Strategy (2008)	See recommendation 4 - Gold Standard Framework for all care homes.
NEAS Business case to extend EOL Transport to weekends – <b>has not been endorsed</b>	All eligible patients should be offered EOL transport 7 days a week
Death Cafes (Good Grief Café in Middlesbrough) well received and provide comfort and good peer support	Provide a safe, confidential space for anyone to come and talk about death and dying in any way they want to
Dementia Friendly Care Home Guide (Designed to help care homes to support, enable and empower residents to live well with dementia by undertaking actions to achieve positive outcomes, which can contribute to CQC regulations and registrations)	Toolkit can encourage Care Homes in Redcar and Cleveland and Middlesbrough to join and form communities of good practice in end-of-life care, share learning and reflecting on good practice. (Include link to guide)
Seniors Connected through Age Friendly Middlesbrough Libraries Project. (In Partnership with MBC Libraries and Public Health)	Addresses chronic Loneliness and increasing volunteering through working with older people from disadvantaged groups.
Know Your Neighbourhood – Creative Lives fund. Creative End of Lives project in Partnership with Together Middlesbrough and Cleveland, Public	Through to second stage of application to secure funding to deliver a creative co-design programme, aimed at engaging with

Health, Borderlands, Teesside Hospice and Aapna Services.	global-majority populations on end-of-life experiences.
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### **South Tees Academy for Palliative and End of Life Care**

The academy for Palliative and End of Life Care is a community of people committed to delivering excellent palliative and end of life care using the experience and expertise of staff across a wide range of organisations in the South Tees locality as well as people with lived experience.

The academy encourages an inclusive approach, challenging traditional stereotypes and considering the needs of people who may find themselves missing out on good palliative and end of life care.

Its role is to build confidence and competence across the workforce, using the experience and expertise of staff across a wide range of organisations in the South Tees locality as well as people with lived experience.

Core activities aim to:-

- Strengthen trust-wide learning around palliative and end of life care
- Strengthen links across organisations through shared learning events
- Build an inclusive culture, improving access to palliative and end of life care for all
- Support the network of palliative care champions across the trust
- Share and co-create materials for use by staff or people using our services
- Learn from examples of good practice, complaints or incidents
- Run educational events and conferences internally and externally

The academy has recruited around 130 PEoL Care Champions who are made up of acute nurses, hospice nurses, community nurses, allied healthcare professionals and chaplains, to promote palliative and end of life care within their own clinical area or departments and act as a link to the specialist palliative care team.

The champions work with their clinical teams to develop best practice in palliative and end of life care whether this is in the acute hospital environment, the community or primary care hospitals and have undertaken this in a variety of ways; including the development of palliative and end of life care poster boards in their teams to share information with colleagues.

<https://www.southtees.nhs.uk/services/test-site/south-tees-academy-for-palliative-and-end-of-life-care/>

## **5.2 What service including commissioned services, are in place to address local needs in relation to this goal?**

Palliative and end of life care is commissioned for the population of Tees Valley from three secondary care providers covering acute and community care, four Hospices and numerous primary care practices and voluntary sector support services. Five Local Authorities also support the social care needs of patients. Core services, such as primary care, community nursing and pharmacy provision are supported by specialist disease specific services in the community and hospitals, plus specialist palliative care services in the community, hospitals, and Hospices. Local Hospice providers also offer

a range of pain management services which complement those provided by community and acute care teams, plus a range of complimentary therapy services.

The North East and North Cumbria Integrated Care Board (NENC ICB) have commissioned the development of a Tees Valley Adult Palliative and End of Life Care Strategy. The Strategy published in December 2023, identified a number of key focus areas linked to the Palliative and end of Life ambitions framework and 2 task and finish groups have been set up to address key areas, progress and key actions including service delivery, funding, contracting and education and training aimed at improving the quality of care for those in need of palliative or end of life care as well as supporting their carers and families.

The NHS England national framework for local action 2021-2026 outlines 6 high-level ambitions that providers and commissioners should seek to achieve in order for people to have the best end of life care. This includes an ambition to encourage all care staff to bring empathy, skills and expertise to any setting and ensure all patients receive more competent, confident, and compassionate care.

Figure 14 ambitions framework for end-of-life care.



Source - NHS England (A national framework for local action 2021-2026)

Research findings on use of the National Framework suggest considerable positive potential of the framework to generate local action as intended. The findings also offer a valuable steer for research

to further understand the issues raised, such as in-depth case study analysis. It is suggested that there is also scope for additional policy and implementation activity that might help to address these issues, including how to bridge the gap, identifying service gaps and commissioning services to address the ambitions.<sup>15</sup>

### 5.3 What are older people’s experiences in relation to this goal?

Patient and stakeholder engagement led by the North East and North Cumbria Integrated Care Board was commissioned as part of the Tees Wide Palliative and End of Life Care Strategy development. Some of issues identified from the patient engagement survey results and interviews were discussed at the JSNA workshop and are included in table 2 below as well as other discussions on people’s experiences in relation to the end-of-life goal.

Table 2 workshop notes – End of Life goal discussions

Workshop notes	Further information and reflections
Inconsistent improvements around advance care planning	See 6.1 Information on Advance Care Planning
Information sharing at late-stage around disease prediction.	See 6.3 Information on conditions relating to palliative and end of life care
General reluctance in talking about death – having difficult conversations.	See 6.4 information on Compassionate approaches to end-of-life care
Mixed messages around palliative care and end of life care.	See recommendation 4 re MOU for Staff Training
Different Clinicians and Teams going into homes resulting in lack of familiarity, safety and awareness.	A strong patient-nurse relationship is built on communication, mutual understanding, and trust. This dynamic encourages patient cooperation, which promotes better health outcomes and increases patient satisfaction.
Some GPs reluctant to discuss advance care planning – and don’t take ownership due to lack of time due to restricted appointment times.	ICB working with primary care to increase the number of Advance Care Plan conversations and the number of plans that are developed and implemented.
Some GPs reluctant to talk to patients about prognosis or end of life due to time constraints	GPs need to increase their capacity to have end of life conversations and will ultimately lead to an increase in their feeling of connection with patients.
Where is ‘the person’ in the planned care – needs a change in policy	See recommendation 1 re patients’ involvement in planned care
DNACPR status not shared with other emergency response services	This policy should apply to all situations in which basic life support, including resuscitation, may be indicated or needed in the context of care service. See X for information on DNACPR policy
Nurses reluctant to do assessment for continued healthcare. dan	CHC assessment is really complex and subjective and therefore prone to inconsistencies, flaws and errors
Need more support for carers around anticipated grief.	Carers Together are supporting Carers around the anticipated death of a loved one, including hospice care and support with day to day living including paying bills etc



## 6. What are the key issues?

### 6.1 Advance Care Planning

Advance care planning is a process of planning for future health and personal care whereby a person's values, beliefs and preferences are identified so they can guide decision-making at a future time when the person is unable to communicate their decisions.<sup>16</sup>

Advance care planning usually consists of 4 broad components:

- Preferences around the types of care or treatment
- Preferences in the place/location where they will be cared for
- Preferences on who they will appoint to be their proxy decision maker for health and financial decisions.
- Official documentation where an individual can detail legally binding advance decisions to refuse certain medical treatments.

An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care and preferred health outcomes. Decisions may be made on the person's behalf, but a person's wishes should be used to guide the decisions.

Everyone approaching the end of life should be offered the chance to create a personalised care and support plan. This should be a holistic assessment developed in conjunction with the patient and families and reviewed on a regular basis. All partners involved in a patient's care should have access to the plan and all should contribute towards one plan.

We need to increase the number of advance care plans that are in place to support patient care planning and enabling patients to communicate what matters to them and their wishes.

### 6.2 Inequalities and End of Life Care

Not all people have the same needs and experiences at the end of their lives, and we need to recognise that, regardless of gender, sexual orientation, relationship or family status, faith, ethnicity, age, disability or socio-economic background, everyone's needs and preferences at the end of life are unique to them.

People from marginalised communities are more likely to experience difficulties in all aspects of end-of-life care, from a disproportionate rate of life-limiting disease burden, as well as reduced access to palliative care. Research shows that there is generally increased vulnerability within populations nearing the end of life. Groups which were recognised as disadvantaged, include people with more complex needs, including homeless, challenging behaviours, learning disabilities, dementia, mental health issues and sensory/ communication difficulties, people in deprived or isolated communities, frail elderly and people in marginalised or discriminated groups; including asylum seekers, people of different ethnicity or faith, LGBTQ+ people, travellers and prisoners.

Research suggests that there may be a number of reasons for these differences. It may be that housing in more deprived areas provides a less suitable environment for end of life care, or that people from more affluent areas can pay for additional support. There may also be differences in local resourcing decisions and spending on services.

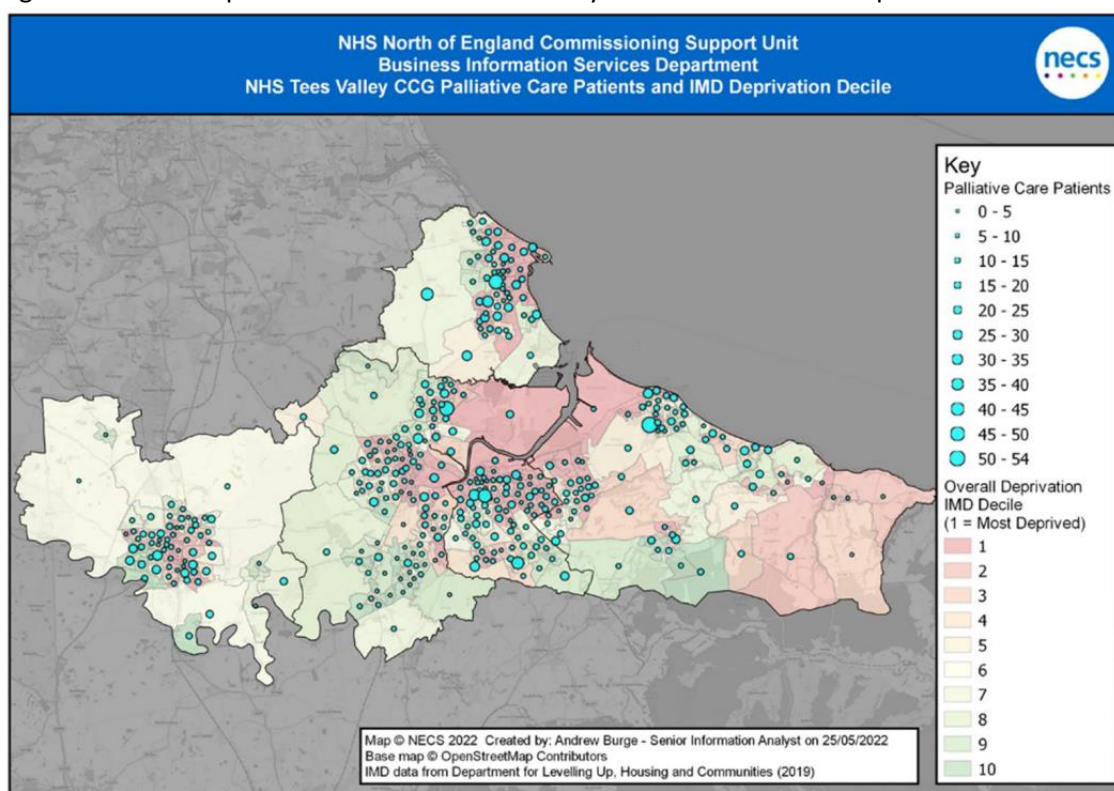
Other Issues include access to specialist health or social care services and the attitudes and behaviours of professionals that impact negatively on service users. In the context of palliative and end of life care, diagnosis can be a barrier, with non-malignant diagnoses often under-represented in specialist palliative care services.

Other practical barriers to healthcare provision include communication difficulties, limited awareness of and access to services, tensions between patients and healthcare professionals and lack of training in delivering culturally appropriate care.

Distinct health beliefs regarding superstitions around illness, personal care, death rituals and bereavement need to be considered in conversations amongst diverse communities. Community diversity requires sensitive and highly individualised approaches to patient care<sup>17</sup>

The North East and North Cumbria ICB suggested that there is the potential for some of the more deprived areas to include populations who are less likely to seek support for their conditions and that there may be a greater need for palliative care need in these areas than is currently understood. Investigation into this correlation may seek to enhance the number of patients from these deprived areas accessing the support they require.

Figure 15: LSOA Deprivation across the Tees Valley and the rate of PEOLC patients



Source – Tees Valley Palliative and end of life care Strategy

Research undertaken by the London School of Economics (LSE) commissioned by Marie Curie, found that there are inequities between those people living in the most and least deprived areas. Evidence showed that there are certain groups of people who receive less palliative care than others with a comparable need. These are people who are over the age of 85, are from black, Asian and minority ethnic (BAME) backgrounds, identify as lesbian, gay, bisexual and transgender (LGBT), are from more

deprived areas, are socially isolated or live alone, are homeless, have mental health needs, or are living in prisons<sup>18</sup>.

It is evident that we need a greater understanding of the needs of these disadvantaged groups, so the service 'offer' reflects that. Systems of end-of-life care would be best designed in collaboration with people who have personal and professional experience of palliative and end of life care<sup>19</sup>. This includes the involvement of clinical staff, particularly nurses, as well as local equality engagement officers and representatives from marginalised groups, supporting the development of the service.

People with serious mental illness have greater mortality risk than the general population. They experience health care inequalities throughout life. People with serious mental illness were also more likely to die in care homes than the general population (Wilson *et al.*, 2020)

There is very little research in the UK, to show how many people with severe mental health issues need palliative care, and how mental health needs are supported for people who are diagnosed with a terminal illness. For people living with terminal illness depression can occur anytime such as following diagnosis, as their disease advances and pain increases, or as their independence becomes more limited. Left unsupported this can have serious implications. Therefore it is vital to consider how palliative care might support someone approaching the end of life with severe mental health conditions such as schizophrenia, bi-polar disorder or clinical depression (Ee, 2021)

### 6.3 Social factors affecting End of Life Care

There are many key challenges, including inequalities in access to end of life support and the relevance of social welfare issues for both patient and carers. Efforts to tackle socioeconomic inequities in access to palliative and end of life care require comprehensive understanding about the extent of and reasons for inequities. Most research on this topic examines differences in receipt of care, comprising four overarching themes: identifying needs; taking action; local conditions; and receiving care (French *et al.*, 2021)

Current models of healthcare services are not meeting the needs of those experiencing socioeconomic deprivation at the end of life. Greater understanding of the needs of disadvantaged groups is needed so the service 'offer' reflects the evidence around causes of crises in the last year of life, in order to have a more proactive approach.

The social, religious and cultural views of medical staff can also have a huge impact on the type of end-of-life offered, and their willingness to make what they can perceive as being ethically 'controversial' decisions on their patients' behalf, according to one study (Seale, 2010)

Those experiencing socioeconomic deprivation have poorer quality of health throughout their life course which can result in poorer quality of death and with decreased access to palliative care services, greater use of acute care, and reduced access to preferred place of care compared with patients from less deprived populations. Studies highlighted three global themes including 1) multi-dimensional symptom burden, 2) preferences and planning and 3) health and social care interactions at the end of life (Bowers *et al.*, 2022)

Being homeless or vulnerably housed is associated with death at a young age, frequently related to medical problems complicated by drug or alcohol dependence. Homeless people experience high symptom burden at the end of life, yet palliative care service use is limited.

Research by (Shulman *et al.*, 2018) documented growing concern that many homeless people are dying in unsupported, unacceptable situations. It highlights the complexities of identifying who is palliative and lack of appropriate places of care for people who are homeless with high support needs, particularly in combination with substance misuse issues. Due to the lack of alternatives, homeless people with advanced ill health often remain in hostels. Conflict between the recovery-focused nature of many services and the realities of health and illness for often young homeless people result in a lack of person-centred care.

There is a need, particularly in the UK, for theoretically driven research that considers both receipt of care and the wider factors influencing the relationship between socioeconomic position and access to palliative and end-of-life care. Further work is needed to understand the disparity in care, particularly around ensuring patients' voices are heard and can influence service development and delivery. Priorities should include: -

- Raising awareness of inequalities around end of life, factors driving them and actions to improve access/standards.
- Cross-agency learning in order to build a more connected, holistic approach.
- Greater understanding of the needs of disadvantaged groups so the service 'offer' reflects that.
- Evidence around causes of crises in the last year of life in order to have a more proactive approach.
- Supporting people to navigate to the best place for their need - this could be through a peer support network – (doesn't need to be a professional role)

A qualitative multiagency stakeholder research exercise (2020) looked at the legal needs of adults with life-limiting illness and how are they managed. A diverse group of professionals representing people with more complex needs including homeless, challenging behaviours, learning disabilities, dementia, mental health issues, communication difficulties; people in deprived or isolated communities; and people in marginalised or discriminated groups, including asylum seekers, Lesbian, Gay, Bisexual, Transgender (LGBT) people, travellers, and prisoners raised concerns around equitable access to care or challenges when interpreting and applying the law. Social welfare legal (SWL) needs were seen to be frequently overlooked in holistic care, impacting negatively on physical and mental health as well as increasing demand on health services.<sup>20</sup>

While there is a broad range of services supporting legal needs in the context of life-limiting illness, spanning health, social care, advice, charitable and legal sectors, it is not clear whether there is consistency in language or approach to these needs and there is no national guidance on when and how services providing advice and support for legal needs associated with ill-health should be engaged, risking variable practice in unmet need. Priorities from the stakeholder research study identified: -

- A need to raise awareness of the breadth of legal issues experienced in life-limiting illness, both with professionals and patients
- Professional education to increase awareness of the breadth of SWL needs
- Closer integration of all relevant agencies, spanning health, social, advice, charitable and legal services to enable holistic care delivery.
- Advice and support offered earlier in a disease journey.
- A toolkit to help professionals navigate legal issues

For people living with terminal illness depression can occur anytime such as following a diagnosis, as their disease advances and pain increases, or as their independence becomes more limited. Left

unsupported this can have serious implications. It is also vital to consider how palliative care might support someone approaching the end of life with severe mental health conditions such as schizophrenia, bi-polar disorder or clinical depression.

## 6.4 Conditions relating to Palliative and end of life care

Palliative care specialists treat people living with many disease types and chronic illnesses. These include cancer, cardiac disease such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, Parkinson's, Amyotrophic Lateral Sclerosis (ALS) and many more. It focuses on the symptoms and stress of the disease and the treatment. It treats a wide range of issues that can include pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite and difficulty sleeping.

There is need for greater recognition of the benefit palliative care provides to those with noncancer conditions, and increased efforts to identify them for palliative care from the point of their terminal diagnosis. This will increase the chance of them having the chance to express a preference in where they would like to receive their care and where they would like to die and put a plan place to achieve this.

Most health-care professionals are trained to promote and maintain life and often have difficulty when faced with the often-rapid decline and death of people with terminal illnesses such as amyotrophic lateral sclerosis (ALS). By contrast, data suggest that early and open discussion of end-of-life issues with patients and families allows time for reflection and planning, can obviate the introduction of unwanted interventions or procedures, can provide reassurance, and can alleviate fear (Connolly *et al.*, 2015)

The end of life care received by patients with advanced dementia and their carers is of increasing importance as the incidence of dementia is set to rise over the next 30 years and onwards. Currently, inappropriate admissions to hospital are common in the UK and patients are less likely to be referred to palliative care services, receive less pain control but undergo more invasive interventions compared to their cognitively intact counterparts. The results showed that participants understanding of dementia and its likely progress was poor. Provision of information regarding the future was rare despite high information needs (Thuné-Boyle *et al.*, 2010)

In medical practice, autonomy is usually expressed as the right of competent adults to make informed decisions about their own medical care. The principle underlies the requirement to seek the consent or informed agreement of the patient before any investigation or treatment takes place.

Patients have a right to adequate relief of their pain and this right is derived from the principles of beneficence, non-maleficence, justice and specifically respect for patient autonomy. At the same time, respect for relational autonomy should be seen as a part of patient autonomy and noted in decision-making.<sup>21</sup>

(Gómez-Virseda *et al.*, 2020) argue that respect for autonomy is a paramount principle in end-of-life ethics. Nevertheless, empirical studies show that decision-making, exclusively focused on the individual exercise of autonomy fails to align well with patients' preferences at the end of life. The need for a more contextualized approach that meets real-life complexities experienced in end-of-life practices has been repeatedly advocated.

Maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care, the emphasis should be also put on supporting the patients engagement in daily activities, in contributing to others, and in active preparation for dying.

## 6.5 Compassionate Communities approaches to end-of-life care

A compassionate community encourages, facilitates, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long-term care.

A compassionate community recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility and can complement health care interventions, by paying attention to prevention, detection, harm reduction, and early intervention. It is where a community of people feel empowered to engage with and increase their understanding about the experiences of those living with a serious illness, caregiving, dying and grieving and those who are isolated, marginalised, or vulnerable.

Compassionate communities involve policies created by communities themselves to actively involve citizens in their own end of life care concerns. In doing so they change social environments, cultures, conduct, and attitudes towards end-of-life experiences and care. It is where members take an active role in caring for people, assist people to live comfortably in their homes, connect people to support, raise awareness about health, well-being and end of life issues, and develop the capacity of others by building supportive networks in the community.

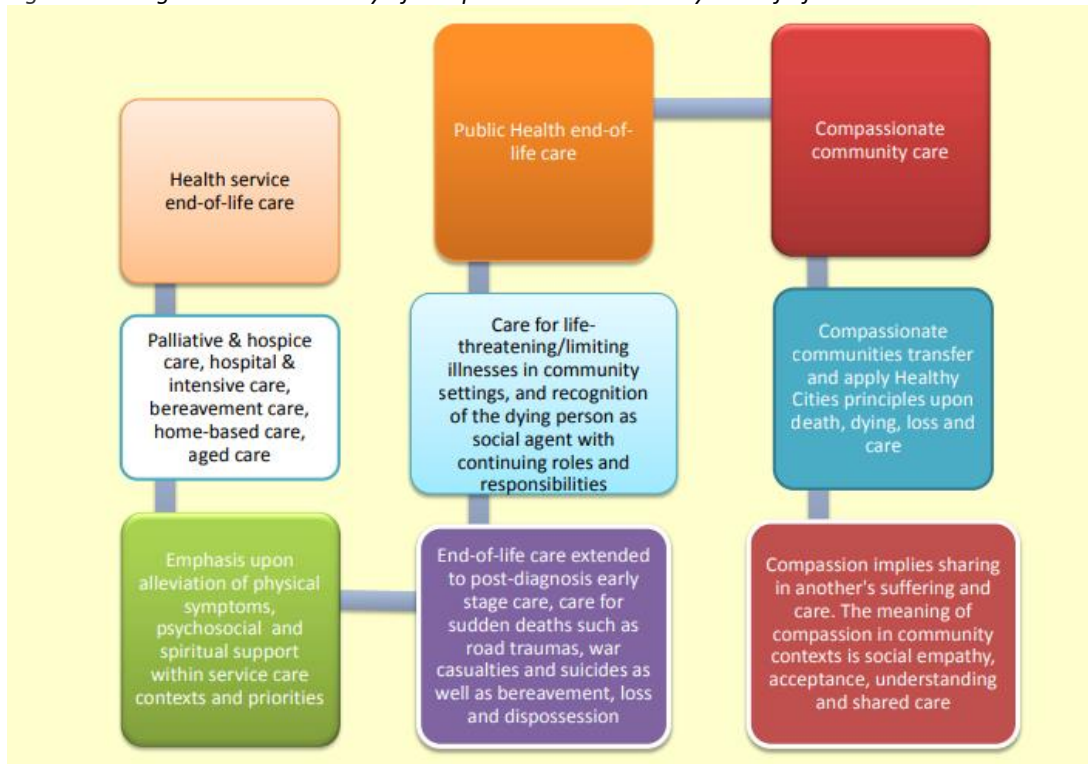
Key elements of a public health approach, including community development and engagement, health promotion and education, are relatively new to end of life care, but have much to offer in creating compassionate communities and promoting the wellbeing of dying, caring, and bereaved people. Educational institutions, workplaces, faith organisations, trade unions and other social organisations and settings can reflect upon their own end-of-life care experiences in order to develop their own local policies and responses to these experiences.

A Public Health England (PHE) toolkit on public health approaches to end of life care states that Services and local authorities play a significant role in providing and sustaining quality end-of-life care, but people from all walks of life should be involved in designing suitable end-of-life care policies that meet their needs.<sup>22</sup>

A PHE research report on Public Perceptions and Experiences of Community-Based End of Life Care Initiatives, suggested that compassionate end of life care is concerned with social efforts led by a coalition of initiatives from governments, state institutions, and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, caregiving and bereavement. These efforts occur through public education, improvement of social capital (trust, empathy and cooperation) and community development, enactment of laws, partnerships with health services and their professionals, and the creation of safe and sustainable social and physical environments.<sup>23</sup>

The figure 16 below is a road map example of the roles and character of health services and public health in compassionate community end-of-life care.

Figure 16: Diagrammatic summary of compassionate community end-of-life care



Source - public health approaches to end-of-life care

Compassionate communities are deep rooted in a health promotion approach to palliative care, aiming to support solidarity among community members at the end of life. Hundreds of compassionate communities have been developed internationally in recent years. However, it remains unknown how their implementation on the ground aligns with core strategies of health promotion.<sup>24</sup> Each community needs to adopt its own approach to building more compassion in response to local needs by: -

- Developing a local approach of sharing the vision, identifying what has already been implemented and what remains to be done and how all sectors can work together for the good of the public.
- Assessment which will consider how to engage social and community networks in the model of care, considering the holistic nature of provision and issues of inequity.
- Looking for unmet needs and shared opportunities.
- Providing a variety of different services relating to the public health approach to the spectrum of chronic disease management, disengaged members of the community in end of life care including bereavement.
- Provide guidance and expertise.
- Provide education programmes on the public health approach.
- Agree to uphold the principles of a Compassionate Community.

Case example of a compassionate community

Alison Bunce an inspirational Nurse from Inverclyde Scotland was awarded Nurse of the Year in 2022 by the RCN for implementing a compassionate community in Inverclyde. The initiative included a collaboration of individuals, faith groups, voluntary bodies and businesses working alongside healthcare professionals to support people in crisis and aimed at putting compassion and kindness first, coordinating services such as end of life companionship. This initiative helped mobilise the community and support people in need and included a Team of volunteers who could provide care packages for discharged patients living alone, and support after bereavement, and help people build connections that boost mental health and wellbeing.

Alison’s 12-step guide for nurses who could be inspired to establish a compassionate community include:

1.	Start with conversations about what matters most to local people
2.	Seek development support from a trusted, compassionate leader
3.	Develop collaborative leadership at all levels around a shared purpose and values
4.	Anchor the movement with a trusted community organisation
5.	Establish a courageous guiding coalition that gives permission to act, avoids unnecessary bureaucracy and enables risk-taking
6.	Connect as ordinary people and find creative ways to make it easy for people to volunteer and for everyone to be kind, helpful, and to have a can-do attitude
7.	Value and empower all contributors and ensure they have a strong and equal voice
8.	Nurture volunteers through peer support, reflective practice and wholehearted facilitation
9.	Use social media to communicate and organise
10.	Stay curious and keep learning from other compassionate communities
11.	Continue to pay attention to what matters to people and share stories that touch hearts and inspire kindness
12.	Plan for a sustainable model of leadership and governance

#### Case Example of compassionate city

Birmingham was accredited as the UK’s first Compassionate City and was recognised for their compassion in the way communities have supported each other during some of the most challenging times. Starting the work towards becoming a Compassionate City during 2019, Birmingham committed to building this aspiration into their Palliative and End of Life Care Strategy.

During 2021 a Compassionate City Network was formed in Birmingham, with a team of people working together across the Compassionate City Charter Standards. The Charter recognises the kindness and compassion across all communities and building on work that had already taken place to ensure all services, schools, employers and citizens could feel confident supporting people living with a serious illness or who are grieving.

*Source: Birmingham City Council*

While there is poor evidence of the implementation and evaluation models of Compassionate Communities and Cities at the end of life and little evidence about compassionate communities development and assessment models, studies argue that a global model for the development and evaluation of compassionate communities at the end of life seems to be necessary (Librada-Flores *et al.*, 2020)



When used in the field of public health palliative care, the term 'compassionate communities' carries inferences not just about the attributes of the community, but also about the methods used to create those communities. Key is recognising the importance of work being led by communities themselves.

Personalised care planning, shared records, evidence and information, involving, supporting and caring for those important to the dying person, education and training, 24/7 access including systems of end-of-life care are best designed in collaboration with people who have personal and professional experience of palliative and EOL care

Even before the start of the COVID-19 pandemic in early 2020, it was inevitable that services would have to change to cope with increasing complexity and numbers if there was going to be any chance of meaningful choice at the end of life in the future. The gaps in the system are more apparent now than ever before and it is clear that the service environment will need to be different in several ways from where, what, when and how services are delivered, to how they are funded. This is vital in making sure everyone can access the services they need, at the right time for them.

## **7. What is the current evidence base?**

See appendix \_ for a summary of the research and evidence on end of life care, compiled by NIHR Health Determining Research Collaboration.

## 8. What do local people say?

The NHS North East North Cumbria Integrated Care Board (NENC ICB) commissioned a comprehensive programme of engagement with the public and stakeholders to support the development and vision of a Palliative and End of Life Care strategy.

This engagement included gathering feedback from those who had supported a loved one with a long-term condition or cancer, during the end stages of their life (in the last two years). This was in the form of an online survey (which achieved 100 responses) which was in-depth and sought to gather feedback across a various range of services that could support a palliative or end of life care patient as well as 1:1 sessions.

Overall (57%) of survey respondents rated their care positively as good, excellent, and outstanding in the last three months of life with 27% rating their care as poor. Respondents provided comments to help improve palliative and end of life care services in Tees Valley, including what else they might need or felt might be useful that was not provided.

Themes that emerged from the survey and 1:1 sessions included

- A need to improve communication with patients, families and carers, both at diagnosis, during the provision of care and at the end of life
- Improved ways for patients, families and carers to make contact with services, helping them to navigate the system to gain access to care in a quick and easy way when this is needed and provide improved co-ordinated care to them
- Opportunities to reflect on the way care is provided to patients, increasing continuity where this is possible and, in some cases, increasing the compassion provided to patients, families and carers

At times some people felt that patients receive an outstanding level of care, but this is not consistent and there is a need to ensure that this outstanding care becomes the norm across the Tees Valley.

Respondents who shared that they were not given the help or support needed, were asked to specify what would have made a difference to them and common themes included more help and support from a variety of services such as District Nurses, Macmillan, Marie Curie, Mental Health and Social Services for both the patient, families, and carers. Sadly, for some they received no help and support, or only when they reached crisis point or when it was too late. Further themes also included joined up care, a single point of contact with regular contact and an emphasis for individuals to be given more information on what could be provided and what to expect.

See appendix b for real life case studies from patients' pathways that were compiled as part of the workshop and interviews undertaken as part of the strategy engagement.

## 9. What are the recommendations?

1.	Improve the early identification of palliative patients to ensure they are supported on their end-of-life journey as soon as possible. Ensuring that patients, families, and carers are better informed, both from a health perspective in managing their advance care planning needs and also from a social welfare perspective.
2.	Ensure care is joined up across health and social care teams to identify patients on the palliative care register who also have other long-term conditions. This should include Improved System Interoperability (i.e., shared access to system one)
3.	Introduce strategies to increase awareness with families, professionals, and wider communities on the variety of social welfare support for end-of-life patients. Addressing health inequalities in palliative and end of life care, to improve equity of access to services and reducing inequity of outcomes and experience. Need to utilise population health management approaches for identifying priority groups.
4.	ICB and South Tees Trust to work collaboratively to review current training programmes for staff (including care homes and GP practices) and agree consistent programmes that focus on provision of good quality palliative and end of life care. (Link with South Tees Academy for PEoL Care)
5.	Look into costs and benefits of investing in Gold Standard Framework to increase the number of accredited GP practices and Care Homes. Option to widen access to care homes and social care.
6.	Ensure that specialist palliative care services are available 7 days a week. This will require a review of community palliative care services commissioned from Trust providers and may require investment into these services.
7.	Explore strategies with primary care to increase the number of care plan conversations and in turn, the number of plans that are developed and implemented.
8.	Develop a public health response to death, dying and loss, extending end-of-life care to community settings using a compassionate approach to end-of-life care, to encourage sustainable responses and networks of care that are adaptable and flexible, depending upon need and demand. This includes upholding the principle of a compassionate community approach and Compassionate Communities UK Accreditation.

## 10. Appendix

### a) End of life Care evidence base and issues



#### End of Life Care: Evidence Base and Issues

*M Din & A Divers*

##### Inequalities and End of Life Care

- Those from marginalised communities are more likely to experience difficulties in all aspects of end-of-life care, from a disproportionate rate of life-limiting disease burden, as well as reduced access to palliative care (Crawley, 2005)
- One hospice sought to address inequalities through establishing an equality steering committee to identify and meet the needs of underrepresented groups in the local community (Lawrance, 2020)
- Traveller and Roma communities are known to experience health inequalities. There has been little focus on palliative care in these communities despite the well-recognised inequalities of access to palliative care in other minority ethnic groups. A wide range of factors influence Gypsy, Traveller and Roma community access to palliative care (Dixon *et al.*, 2021)
- The NHS Long Term Plan commits to improving personalised palliative and end of life care for people of all ages and to address health inequity. The Local Government Association and Association of Directors of Adult Social Services' guide emphasises the role of councils in this area (National Palliative and End of Life Care Partnership, 2021)

##### The main recommendations put forward by the above papers include:

- The involvement of clinical staff, particularly nurses, as well as local equality engagement officers and representatives from marginalised groups, supports the development of service improvement plans.
- Community diversity requires sensitive and highly individualised approaches to patient care.
- Distinct health beliefs regarding superstitions around illness, personal care, death rituals and bereavement must be considered within conversations amongst diverse communities
- Practical barriers to healthcare provision include communication difficulties, limited awareness of and access to services, tensions between patients and healthcare professionals and lack of training in delivering culturally appropriate care.
- Establishing a committee to promote fairer access to palliative care services by raising awareness of equality issues, removing barriers and addressing the challenges in achieving high-quality, end of life care.
- Personalised care planning, shared records, evidence and information, involving, supporting and caring for those important to the dying person, education and training, 24/7 access,

systems of EOL care are best designed in collaboration with people who have personal and professional experience of palliative and EOL care.

### **Social Factors affecting End of Life Care**

- The social, religious and cultural views of medical staff can have a huge impact on the type of end-of-life offered, and their willingness to make ethically 'controversial' decisions on their patients' behalf (Seale, 2010)
- Those experiencing socioeconomic deprivation have poorer quality of health throughout their life course which can result in poorer quality of death – with decreased access to palliative care services, greater use of acute care, and reduced access to preferred place of care compared with patients from less deprived populations. Three global themes were identified: 1) multi-dimensional symptom burden, 2) preferences and planning and 3) health and social care interactions at the end of life (Bowers *et al.*, 2022)
- Efforts to tackle socioeconomic inequities in access to palliative and end-of-life care require comprehensive understanding about the extent of and reasons for inequities. Most research on this topic examines differences in receipt of care, comprising four overarching themes: identifying needs; taking action; local conditions; and receiving care (French *et al.*, 2021)
- Being homeless or vulnerably housed is associated with death at a young age, frequently related to medical problems complicated by drug or alcohol dependence. Homeless people experience high symptom burden at the end of life, yet palliative care service use is limited. This research documents growing concern that many homeless people are dying in unsupported, unacceptable situations. It highlights the complexities of identifying who is palliative and lack of appropriate places of care for people who are homeless with high support needs, particularly in combination with substance misuse issues. Due to the lack of alternatives, homeless people with advanced ill health often remain in hostels. Conflict between the recovery-focused nature of many services and the realities of health and illness for often young homeless people result in a lack of person-centred care (Shulman *et al.*, 2018)

### **The main recommendations put forward by the above papers include:**

- ❑ Current models of healthcare services are not meeting the needs of those experiencing socioeconomic deprivation at the end-of-life. Further work is needed to understand the disparity in care, particularly around ensuring patients voices are heard and can influence service development and delivery.
- ❑ There is a need, particularly in the UK, for theoretically driven research that considers both receipt of care and the wider factors influencing the relationship between socioeconomic position and access to palliative and end-of-life care.
- ❑ Attempts to address any inequities in access will require knowledge and action across many different areas. Key evidence gaps in the UK literature concern the relationship between socioeconomic position, organisational context, and assessing need for care.
- ❑ Greater multidisciplinary working extended in-reach into hostels from health and social services and training for all professional groups along with more access to appropriate supported accommodation are required to improve care for homeless people with advanced ill health.

### **Specific Conditions**

- Palliative care practices, including communication about patient-centred goals of care and advance care planning (ACP), have the potential to enhance care throughout the course of Huntington's disease (HD) and related disorders. Provision of primary palliative care for HD in

an interdisciplinary clinic is feasible. Integration of palliative care practices into HD specialty care requires additional training and modification of clinic operations (Harrison *et al.*, 2023)

- Most health-care professionals are trained to promote and maintain life and often have difficulty when faced with the often-rapid decline and death of people with terminal illnesses such as amyotrophic lateral sclerosis (ALS). By contrast, data suggest that early and open discussion of end-of-life issues with patients and families allows time for reflection and planning, can obviate the introduction of unwanted interventions or procedures, can provide reassurance, and can alleviate fear (Connolly *et al.*, 2015)
- The end-of-life care received by patients with advanced dementia and their carers is of increasing importance as the incidence of dementia is set to rise in the next 30 years. Currently, inappropriate admissions to hospital are common in the UK and patients are less likely to be referred to palliative care services, receive less pain control but undergo more invasive interventions compared to their cognitively intact counterparts. The results showed that participants' understanding of dementia and its likely progress was poor. Provision of information regarding the future was rare despite high information needs (Thuné-Boyle *et al.*, 2010)

**The main recommendations put forward by the above papers include:**

- ❑ Patients' perspectives regarding end-of-life interventions and use of technologies might differ from those of the health professionals involved in their care, and health-care professionals should recognise this and respect the patient's autonomy. Advance care directives can preserve autonomy, but their legal validity and use varies between countries.
- ❑ Clinical management of the end of life should aim to maximise quality of life of both the patient and caregiver and, when possible, incorporate appropriate palliation of distressing physical, psychosocial, and existential distress. Training of health-care professionals should include the development of communication skills that help to sensitively manage the inevitability of death.

**Mental Health and End of Life Care**

- People with serious mental illness have greater mortality risk than the general population. They experience health care inequalities throughout life. People with serious mental illness were more likely to die in care homes than the general population (Wilson *et al.*, 2020)
- There is very little research in the UK, to show how many people with severe mental health issues need palliative care, and how mental health needs are supported for people who are diagnosed with a terminal illness
- Certain groups of people receive less palliative care than others with a comparable need. These are people who are over the age of 85, are from black, Asian and minority ethnic (BAME) backgrounds, identify as lesbian, gay, bisexual and transgender (LGBT), are from more deprived areas, are socially isolated or live alone, are homeless, have mental health needs, or are living in prisons.
- For people living with terminal illness depression can occur anytime such as following diagnosis, as their disease advances and pain increases, or as their independence becomes more limited. Left unsupported this can have serious implications. It is also vital to consider how palliative care might support someone approaching the end of life with severe mental health conditions such as schizophrenia, bi-polar disorder or clinical depression (Ee, 2021)

### **The main recommendations put forward by the above papers include:**

- ❑ Given that people with serious mental illness have increased mortality risk, this gap in the knowledge around end-of-life care outcomes is concerning; this area of research needs further development.
- ❑ There is a need for A Die Well life stage added to the mental health strategy to fully address the mental health needs of people approaching the end of life; More research to show how many people with severe mental health issues need palliative care, and how mental health needs are supported for people who are diagnosed with a terminal illness; better communication and understanding between palliative care and mental health teams, and wider education and training to support practitioners in palliative care and anticipatory care planning skills; More support for families and carers of people with a terminal illness or at the end of life through the course of their condition and support during bereavement

### **Accessing Support**

- The Carer Support Needs Assessment Tool encompasses the physical, psychological, social, practical, financial, and spiritual support needs that government policies in many countries emphasize should be assessed and addressed for family caregivers during end-of-life care. The overwhelming majority reported finding the Carer Support Needs Assessment Tool assessment process straightforward and easy. Four key themes were identified: (1) the practicality and usefulness of the systematic assessment; (2) emotional responses to caregiver reflection; (3) validation, reassurance, and empowerment; and (4) accessing support and how this was experienced (Aoun *et al.*, 2015)
- Gateshead Council has developed an approach of understanding needs at an individual level. This takes conversations away from defined checklists and makes it more personalised. This is a big cultural shift to consider for palliative/EOL care. [The Liberated Method - Rethinking public service \(changingfuturesnorthumbria.co.uk\)](http://changingfuturesnorthumbria.co.uk)

### **The main recommendations put forward by the above papers include:**

- ❑ The Carer Support Needs Assessment Tool presented a simple, yet potentially effective intervention to help palliative care providers systematically assess and address family caregivers' needs. The Carer Support Needs Assessment Tool provided a formal structure to facilitate discussions with family caregivers to enable needs to be addressed.

### **Autonomy and Choice**

- The predominating definition of autonomy as a capacity to make an independent rational choice may not be suitable for patients in palliative care. Therefrom arises the actual need for more contextualized perspectives on autonomy to promote the quality of life and satisfaction with care of terminally ill patients (Houska & Loučka, 2019)
- Patient autonomy in healthcare is bounded, as while patients were generally encouraged to express their preferences for care, medical norms about the quality and 'reasonableness' of care, the availability of services and the patients' family relationships act to enhance or limit patients' capacity to realize their preferences. Autonomous palliative care programs (an initiative currently in place within Canada which actively consult patients and families about the trajectory of palliative care) therefore, may be rejected by healthcare professionals as irrelevant to care or may have the unintended consequence of limiting patient autonomy when used as a professional tool to encourage a 'right' way to die (Johnson *et al.*, 2018)

- Respect for autonomy is a paramount principle in end-of-life ethics. Nevertheless, empirical studies show that decision-making, exclusively focused on the individual exercise of autonomy fails to align well with patients' preferences at the end of life. The need for a more contextualized approach that meets real-life complexities experienced in end-of-life practices has been repeatedly advocated (Gómez-Vírseda *et al.*, 2020)

**The main recommendations put forward by the above papers include:**

- ❑ Maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care but that emphasis should be also put on supporting the patients' engagement in daily activities, in contributing to others, and in active preparation for dying.
- ❑ A singular focus on bureaucratic Autonomous Palliative Care programs, mentioned above, which reduce patient autonomy to a 'tick box' exercise, may fail to enhance End Of Life care in any meaningful way.
- ❑ Autonomy entails more than merely possessing cognitive capacity and autonomy is not a binary 'all – or – nothing' notion but rather a multidimensional capacity. Often, this makes autonomy more complex and less neat. This, however, is a fair price to pay when focusing on "actual autonomy" and not on "ideal autonomy". Focusing on actual autonomy brings ethical reflection to bear on the mundane, interstitial, ongoing reality, rather than on idealized crises or problems. Rather than creating neat procedural outcomes for hypothetical ethical conflicts, relational ethics is particularly helpful in guiding day-to-day ethical situations that occur between real people.

**Compassionate and Community Care**

- Promoting good social, psychological, spiritual as well as physical health while living with a life-limiting illness makes good sense. Involving schools, workplaces, places of worship, the mass media or local businesses could help mobilize untapped sources of social and spiritual care and support as well as practical resources (Kellehear, 2013)
- There is poor evidence of the implementation and evaluation models of Compassionate Communities and Cities (CCC) at the end of life. There is little and low-/very low-quality evidence about CCC development and assessment models. We found no data published on care intervention in advance disease and end of life. A global model for the development and evaluation of CCC at the end of life seems to be necessary (Librada-Flores *et al.*, 2020)
- Over the last decade or so, the public health approach to end of life care has increasingly been adopted and advocated by international palliative care services (Kellehear, 2015)

**The main recommendations put forward by the above papers include:**

- ❑ End-of-life care, like contemporary health care as it currently exists, could partner with community efforts to provide support and care for death, dying, loss and practical caring. Families and palliative care, dementia care or bereavement care services for examples, would not be alone in shouldering the responsibility for these kinds of care.
- ❑ A global model for the development and evaluation of CCC at end of life care seems to be necessary. Systemizing the processes will help emergent organizations or communities to develop Compassionate Communities and Cities and it will facilitate the assessment or its impact and effectiveness.
- ❑ The introduction of a *Compassionate City Charter* may help to establish networks for those facing the need to access palliative care, and their families/carers.



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## **b) Case Studies from the Tees Valley Palliative and end of Life Care Strategy patient and stakeholder engagement**



Clare's Story.docx



Denise's Story.docx



Rebecca's Story.docx



Trudy's Story.docx



Angela's Story.docx

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