

End of Life Care Strategy for Adults 2017 - 2020



Version Control

Document version control		
Version	Date	Comments
V0.1	09/08/2017	Final draft reviewed and agreed by End of life programme board – minor amendments made.
V0.2	06/09/2017	Final draft reviewed and agreed by Commissioning Committee – reference to social isolation strategy included, and clarification that strategy is for adults.
V0.3	27/09/2017	Final draft for review by the Governing Body.

This strategy has been developed in partnership with:



1. Our Vision

Patients and their carers need end of life care that allows them to express their preferences and meets their needs. This care should be integrated and delivered with continuity and consistency. Providing the opportunity of a good death lies at the heart of this document, we have identified our local priorities by using the national ambitions for end of life care as a framework for developing this strategy and delivering our local vision.

Our vision is to ensure that everyone approaching their end of life receives consistent and high quality care. We want to make the last stage of life as good as possible with everyone working together to ensure that patients and the people who are important to them (including carers) are supported. We want to support people to die in a place of their choice with the support they, their families and carers need to allow that to happen.

In the first year we will

- Make changes to current service provision to ensure that more patients are supported to achieve their preferred place of death.
- Identify opportunities to enhance training and development to ensure professionals feel confident in identifying patients in the last year of their life and in having conversations about dying, death and bereavement.
- Make improvements to how we record patient's plans, wishes and priorities for their care in the future, and improve patients knowledge on how to access care and support.

In the second year we will

- Continue to talk more openly about dying, death and bereavement to increase awareness so that patients are able to make plans for the end of their life.
- Support more patients to die in their preferred place of death, and have better links within local communities.
- Design new end of life model of care with agreed timeline for delivery.

By year three we will

- Commission and implement a new model of care that provides a universal offer for end of life care to all patients that supports their choice irrespective of background, race or religion.

2. End of Life Care Definition

This strategy uses widely accepted definitions of end of life care. The definitions of 'end of life' are those as defined in the *One Chance to Get it Right* report, produced in June 2014 by the Leadership Alliance for the Care of Dying People. This definition is also used in the *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020* produced in 2015 by the National Palliative and End of Life Care Partnership. This definition is as follows:

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

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

2.1. End of Life Care

End of life care is care that helps people with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes: [01] [02]

- Care provided to all adults with advanced, progressive, incurable illness (such as heart failure, advanced cancer, dementia, chronic pulmonary disease, stroke, chronic neurological conditions e.g. multiple sclerosis, motor neurone disease)
- Care provided in the last year of life (pain management and control of other symptoms)
- Provision of social, psychological, spiritual and practical support for patients and their carers
- Care provided in all settings (home, residential and nursing care homes, acute hospital, community hospitals, hospices, prisons and any other institutions)

This strategy is for adults who are 18 years and older.

2.2. Who's at risk and why?

The National Audit Office's report on end of life care suggests that approximately 40% of patients dying in acute hospitals do not have medical needs requiring hospital stay.[03] In Medway, this equates to about 408 people annually. The report suggests that people approaching end of life and their families are at a difficult time and may be at risk of poor end of life experience if their needs are not being met because they are in an inappropriate setting and therefore, not receiving the right and appropriate level of care and support. This issue is exacerbated for patients with a non-cancer diagnosis. Early recognition of end of life

is particularly problematic for patients with non-cancer diagnosis as traditionally, end of life services have been provided only to cancer patients.

Around half a million people die each year in England. The majority of these deaths occur in people over 65 following chronic illnesses related to long term conditions such as cancer, heart disease, renal disease, liver disease, chronic respiratory disease, neurological diseases including dementia.[02] This implies, that the proportion of anticipated deaths from a long term condition can be estimated. However, comparison with the number of patients registered on the Quality Outcomes Framework (QOF) palliative care register indicates that patients are not currently being identified in the last year of life. This suggests that adults diagnosed with chronic long term illness nearing the end of life, are at risk of not gaining access to optimal end of life care.

The Royal College of General Practitioners published the Prognostic Indicator Guidance in 2008.[04] This was to assist GPs identify patients who would most likely require end of life care in the coming year and thus provide through the QOF palliative care register, a more realistic estimate of need.

2.3. Why is a strategy needed?

People approaching end of life, often have complex needs, requiring support from different agencies in various locations. The National End of Life Care Strategy [02] indicates that the majority of people would prefer to die at home. Yet in 2016, there were 2142 deaths in Medway, with 47.6% (1020) of these occurring in hospital, 24.7% (529) at home and 10.4% (222) in care homes. This highlights the need for change and why locally we need to focus on identifying opportunities for health and social care systems to work together to provide coordinated care and support, opportunities for patients to discuss their personal needs, choice of where to be cared for and to die, with appropriate advice and support for carers at every stage.

3. Drivers for change: End of life care priorities

3.1. National priorities

End of life care is central to wider reform and transformation being delivered under the NHS Five Year Forward View published in October 2014 to ensure that increasingly care is provided in community settings and available much closer to people's homes. End of life care is firmly embedded as core business for the NHS in the future.

The mandate from the Government to NHS England: April 2017 to March 2018 sets out the government's objectives for the NHS and is clear that it must meet the the needs of each individual with a service where people's experience of their care is seen as an integral part of overall quality. It adds that people should be empowered to shape and manage their own health and care and make meaningful choices including those set out in the Government's response to the End of Life Care Choice Review.

For most of us, talking about death feels awkward, and difficult. But we have a great opportunity now, across the NHS, to have those conversations about people's hopes (and fears) for the end of their life.

The way that we will be able to do this is framed by six clear commitments from the Government to improve end of life care, published in July 2016 in response to the Review of End of Life Care. The Government commissioned the Review of Choice in End of Life Care to provide independent advice on improving the quality and experience of care for adults at the end of life, their carers and others who are important to them, by expanding choice.

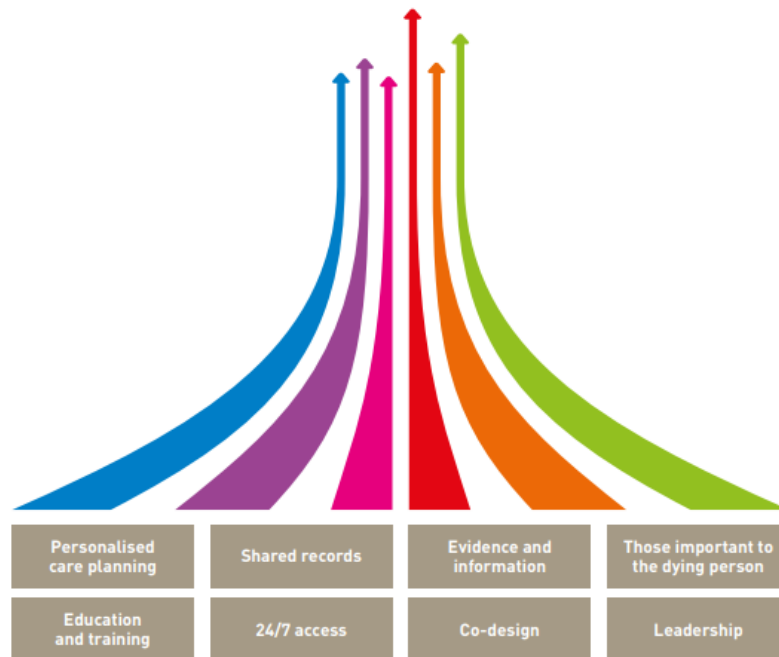
The Government's commitment is aligned with the Ambitions for Palliative and End of Life Care outlined by the National Palliative and End of Life Care Partnership in 2015 which the Government state provides *'a framework for national and local health and care system leaders to take action to improve end of life care.'*

The two key national drivers for End of Life care are detailed below –

- **Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care** was published in July 2016 by the Government. It is a national commitment to end of life care outlining the actions the Government is taking to ensure that everyone has access to *'high quality, personalised end of life care built around their needs.'* It encapsulates what everyone should be offered as they approach their end of life. Six commitments within this stress that people should be given the opportunity and support to:
 - have honest conversations
 - make informed choices about their care
 - develop and document a personalised care plan
 - share that plan with their care professionals
 - involve, to the extent they wish, their families, carers and those important to them
 - know who to contact if they need help and advice at any time.
- **Ambitions for Palliative and End of Life Care:** A national framework for local action 2015-2020 was published in 2015. It reframes the government's 2008 National End of Life Care Strategy placing person-centred care at the forefront and presents six ambitions, based on collective experience and analysis of the many reviews and reports in to this area of care, along with what is needed to realise these ambitions. The ambitions are the driving force for current innovation and initiatives in end of life care, they are.



To realise this vision eight foundations have been identified that need to be in place to achieve the ambitions.



Foundations for the ambitions

Additional key national drivers are given below:

- End of life care core skills education and training framework commissioned and funded by Health Education England and developed in collaboration with Skills for Health and Skills for Care, published in 2017.
- NICE Quality standards 2017 End of life care for adults
- Hospice UK 2017 No painful compromise
- CQC A different ending: Addressing inequalities in End of life care 2016
- One chance to get it right 2014
- Department of Health 2009 Quality Markers and measures for End of Life care

- **National Bereavement Survey (VOICES)**

The National Survey of Bereaved People (VOICES) seeks the views of informal carers. The results from the 2015 VOICES survey, is from September to December 2015. The aim of the survey was to assess experiences of care in the last three months of life for adults and establish a systematic record of the quality of care experienced by people and their families at end of life.

Key points from this are listed below:

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- Out of the 7,561 responses, the majority believed the deceased had wanted to die at home (81%), 8% said they wanted to die in a hospice, 7% in a care home, 3% in hospital and 1% somewhere else.

- 34% of respondents said they knew of patients preferred place of death, and of these 61% were cancer related deaths.
- 49% of respondents strongly agreed that support from health care professionals from across the different settings is sufficient for patients to stay at home. In contrast only 30% of respondents confirmed they felt supported when the death occurred in hospital.
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%).

The survey overall highlights that whilst respondents felt that overall quality of care was good there needs to be a wider focus in end of life care than those dying with cancer. It highlights the need to encourage conversations and advance care planning to ensure that patients are able to make a choice of preferred place of death, and it is recorded. End of life care policies are giving increasing emphasis to providing good quality care which meets the wishes of the individual including ensuring that a person is able to die in their place of choice. It is also clear that more needs to be done to ensure that awareness is raised about choice and recording people's wishes. This includes with all health and social care professionals.

3.2. Local Priorities: the level of need in the Medway population

Mortality From 2007 to 2016, sudden deaths accounted for about an average 20% of deaths in Medway. Table 1 shows that in 2016, there were over 2,142 deaths in Medway, implying that 1,778 (83%) people in Medway who died that year may have benefited from an end of life care.

Year	Sudden Death	Not sudden death	Total number of Deaths	% of Not Sudden Death
2007	414	1455	1869	77.8
2008	495	1615	2110	76.5
2009	396	1613	2009	80.3
2010	391	1698	2089	81.3
2011	404	1607	2011	79.9
2012	400	1730	2130	81.2
2013	378	1693	2071	81.7
2014	421	1806	2227	81.1
2015	421	1892	2313	81.8
2016	364	1778	2142	83.0

Table 1: Total number of deaths and proportion of sudden deaths in Medway 2007-2016
(Source PCMD- Primary care Mortality database)

Figure 1 show that the majority of deaths in 2016, which were not sudden (1778), occurred following a period of chronic illness, where deaths could have been anticipated and care properly planned.

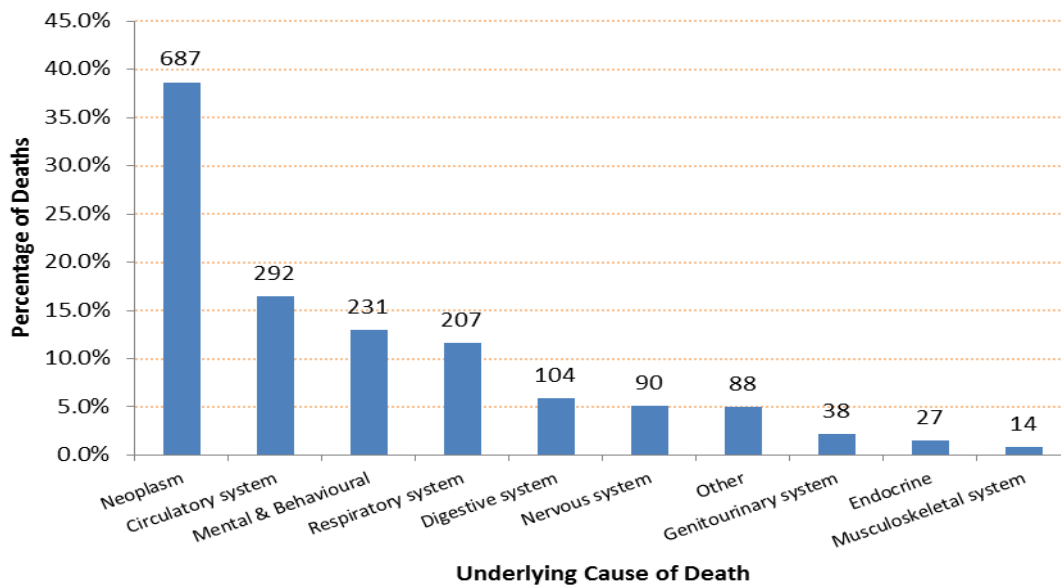


Figure 1: Number of **Not sudden deaths** registered in 2016 in Medway by underlying cause of death

The four main diseases which contributed to 79.7% of all deaths were: cancers (neoplasms) - 687 deaths (38.6%); circulatory diseases- 292 deaths (16.4%); Mental & Behavioural -231 deaths (13.0%); respiratory diseases -207 deaths (11.6%). With active case finding and good disease management the majority of these deaths could be anticipated and the end of life adequately planned for.

Death rates increase steeply with age, with 81.9% (1,755) of deaths occurring in people aged over 65 years and 62.3% (1,335) in people over 75.

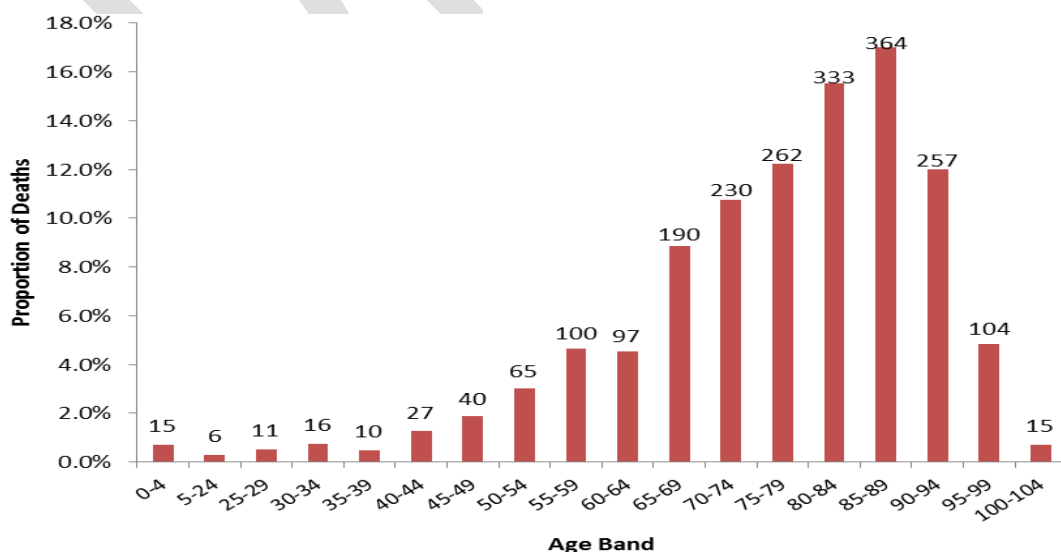


Figure 2: Total Deaths (2142) registered in 2016 in Medway by age band

Place of death, most people die in hospital, although their preferred place of death would be at home as long as high quality care is received with minimal burden to their families and carers¹.

Figure 3 and Figure 4 below shows the place of deaths recorded in 2016 for Medway residents by type of death (Source PCMD).

Figure 3 (below): Place of death (**Not sudden death, 1778**)

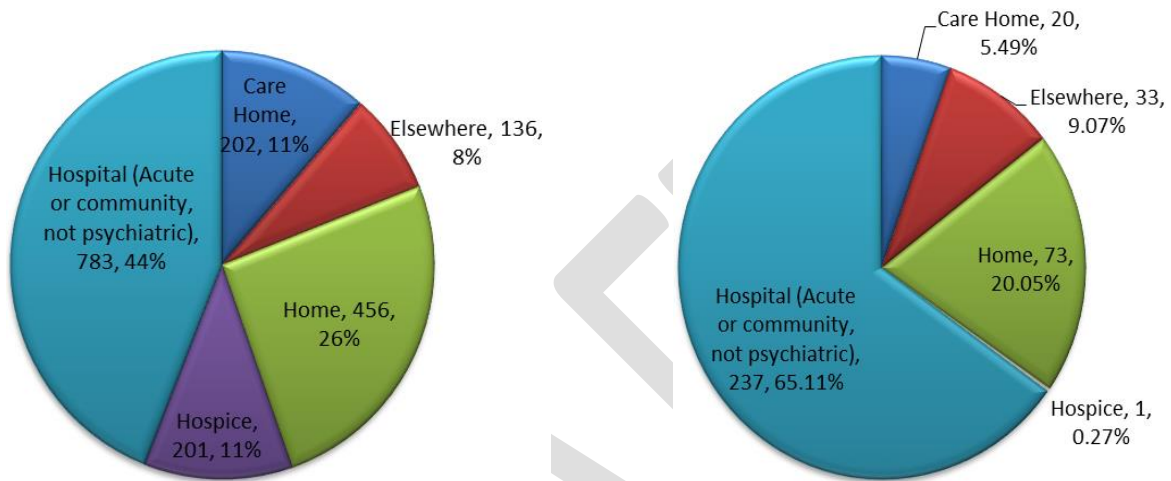


Figure 4 (above): Place of death (**Sudden death, 364**)

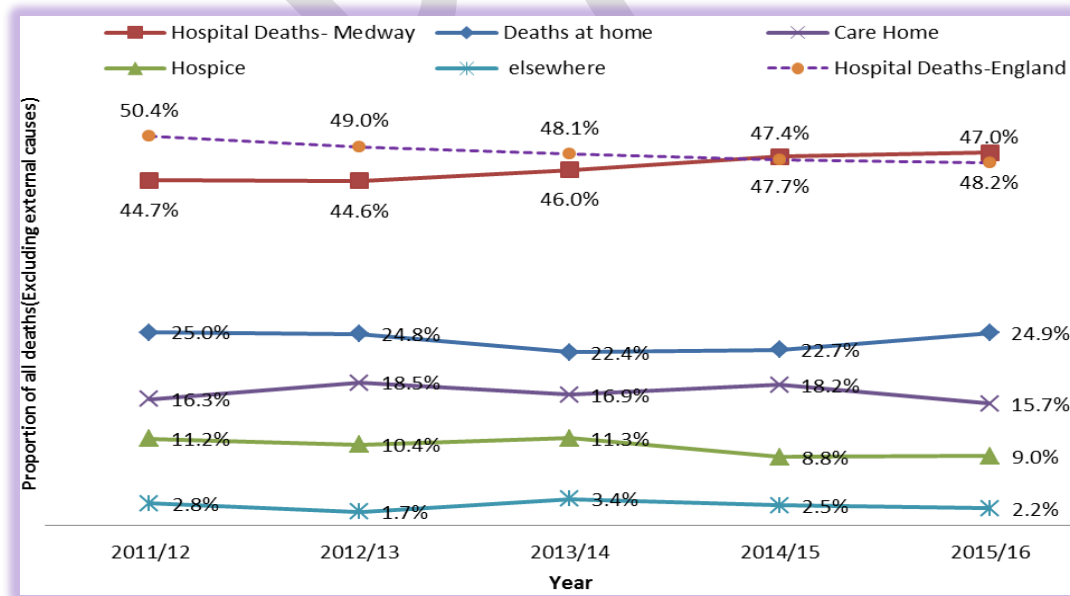


Figure 5: Trends in place of all deaths in Medway²

¹ http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

² http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

In Medway, the proportion of deaths in hospital has risen from 44.7% in 2011/12 to 48.2% in 2015/16 (*Hospital deaths include deaths in Community Hospital*) while during the same period, proportion of deaths in hospital for England has fallen from 50.4% to 48.2%. During the same period, the proportion of deaths occurring at people's homes has stayed approximately the same around 25% for Medway. Figure 5 suggests further work is still needed to ensure equality in access to services for all relevant conditions. It is worth noting that, more deaths, especially due to respiratory conditions tend to occur during the winter months, between December and March each year.

Figure 6 shows that from age 75 onwards the proportion of people dying in hospital increases exponentially (figures are suppressed due to low numbers in certain age bands).

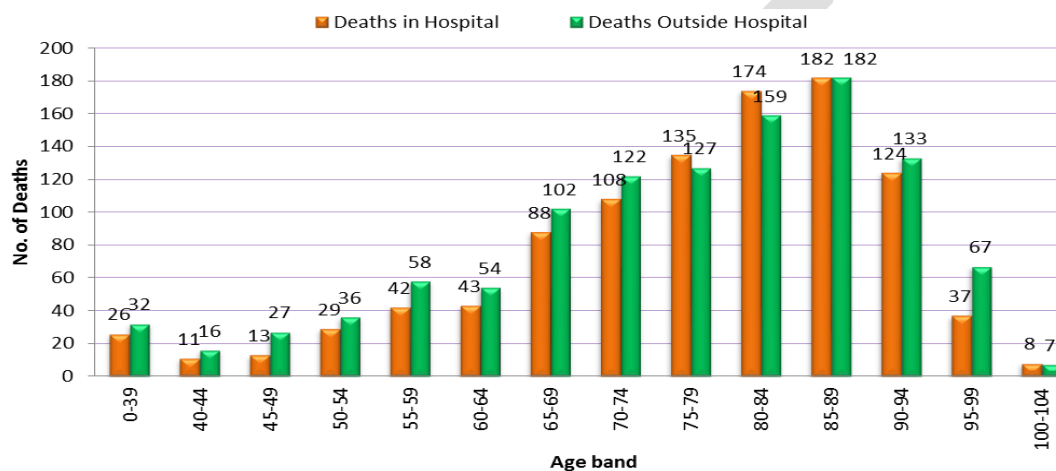


Figure 6: Total Number of deaths (2142) registered in Medway (2016) by age band and place

4. Palliative care register

Identifying patients who are coming to the end of life is key to better palliative care, allowing for coordination and planning of care, prevention of crisis and support for families and carers. Maintaining a register of patients who are approaching the end of life is a tool to allow for better care planning and coordination.

4.1. Identification and palliative care need

The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results. The following table shows the numbers of patients who have been included in the QOF indicator specifically focused on palliative care.

The guidance for this indicator is that they should be included if their death in the next 12 months, can be reasonably predicted, they have advanced or irreversible disease and clinical indicators of progressive deterioration or if they are entitled to a DS1500 form; this form can be used to help patients rapidly access welfare benefits.

Table 2 suggests that Medway identifies a lower percentage of patients with a palliative care need when compared to the UK average. It follows therefore that a larger number of

patients will not have a palliative care plan in place and are more likely to die in hospital³.
(Gold Standard Framework- 3 Steps; Plan Their Care)

Indicator	Description	NHS Medway CCG	UK average
No. with palliative care need	The estimated number of the population within each area that required palliative care per year during the period 2010-2012	1,595	1,796
% of population with palliative care need	The estimated percentage of the population within each area that required palliative care during the period 2010-2012	0.59	0.67
% of population with palliative care need identified	The number of individuals recorded on the primary care (GP) Palliative Care Register in each area in April 2012 - March 2013, as a percentage of the total number of individuals with palliative care needs in the same area	29.71	37.03
% of all deaths with palliative need identified	The number of individuals recorded on the primary care (GP) Palliative Care Register in each area in April 2012 - March 2013 (UK), as a percentage of the average number of deaths in those areas 2010-2012	0.23	0.28

Table 2 Palliative care need and identification (Marie Curie End of Life Care Atlas)

4.2. Palliative care register within Medway GP practices

GP practices should hold a register of all their palliative care patients and should be reviewed 3 monthly. Patients on this register should be reviewed on a three monthly basis by the practice health care team. A form DS 1500 should be issued if requested by a patient (or their representative) if it is identified that the patient may be suffering from a potentially terminal illness.

Table 3 shows the numbers of patients who have been included in the following indicator over the 3 year period.

	2013-14		2014-15		2015-16	
	Register(Count)	Prevalence (per cent)	Register(Count)	Prevalence (per cent)	Register(Count)	Prevalence (per cent)
Rochester and Strood	146	0.16	182	0.19	174	0.18
Lordswood and Chatham	170	0.23	166	0.20	222	0.24
Rainham and Gillingham	132	0.22	183	0.28	158	0.27
Medway Avg.		0.20		0.22		0.23

TABLE 3. NUMBERS ON QOF REGISTERS BY GEOGRAPHICAL AREA (HUB) AND YEAR

Figure 7 shows that while overall there is a slight increase in the number patients being placed on palliative care registers within Medway GP practices over the time period, there is

³ <http://www.goldstandardsframework.org.uk/cdcontent/uploads/files/Library.%20Tools%20%26%20resources/The%20Gold%20Standards%20Framework%20is%20pivotal%20to%20palliative%20care.pdf> – page 34, plan their care

⁴ <http://www.content.digital.nhs.uk/catalogue/PUB22266>

an irregular trend over the time period within localities. Rainham and Gillingham seems to be recording higher number of patients on the palliative care register compared to other 2 other hubs, Rochester and Strood being the consistently lowest over the observed time period.

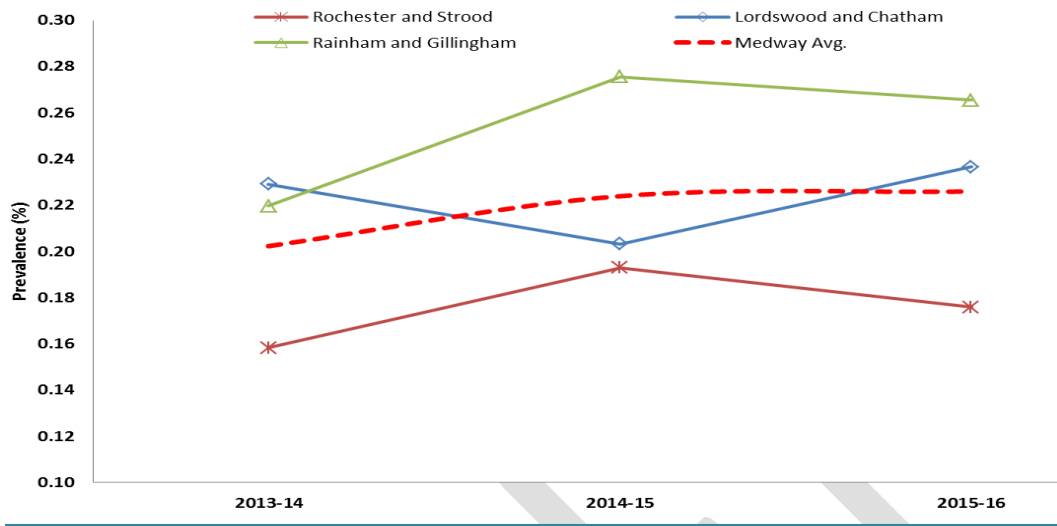


Figure 7: Recorded Prevalence on QOF registers by hub and year

There are about 2000 deaths per year within Medway area. It is recognised that the number of deaths per year is about 1% of a GP practice caseload and there are national campaigns to encourage GPs to identify these patients, 'Find Your 1% Campaign' (see <http://dyingmatters.org/gp>).

It is widely accepted that there are more patients living with cancer on the end of life care Register than non-cancer. The disease trajectory of cancer (Figure 8 blue graph) shows a rapid decline at the end of life phase⁵. The disease trajectory for heart and lung failure conditions (purple graph) shows a more erratic trend of decline and recovery. This makes it more difficult to predict the end of life phase. Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care, are the key steps in the provision of high quality care at the end of life in general practice.

5

<http://www.goldstandardsframework.org.uk/cdcontent/uploads/files/Library,%20Tools%20%26%20resources/The%20Gold%20Standards%20Framework%20is%20pivotal%20to%20palliative%20care.pdf>

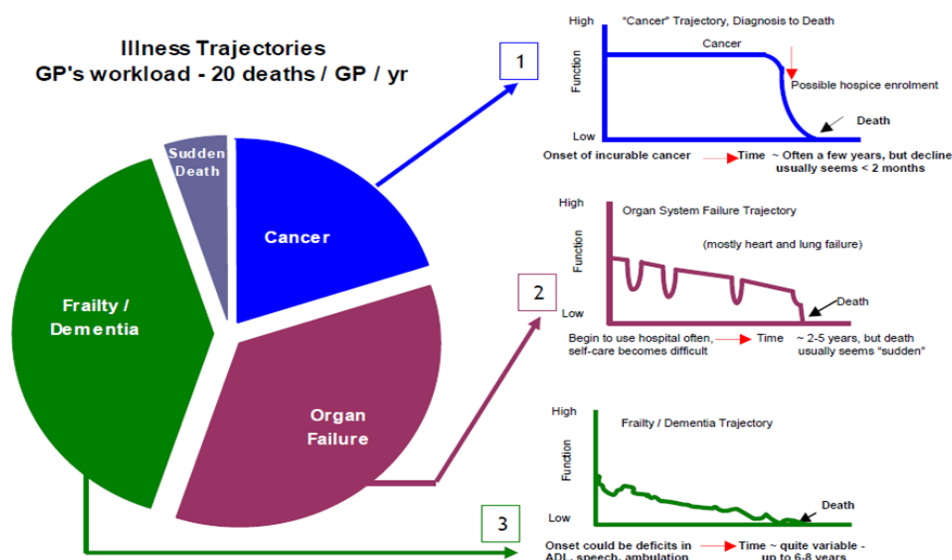


Fig 8: The three main illness trajectories and deaths / GP / year and end stage illness (Assuming GP list size of 2000 patients) After Lynn et al in WHO Guidance Palliative Care the Solid Facts Ed Higginson

Continuity of care for these patients can be achieved with the allocation of a keyworker able to proactively plan their care in partnership with the patient. Examples of key workers are a Community Nurse, Nurse Case Managers or Clinical Nurse Specialist.

4.3. Projected level of need

Table 4 below shows population projections for the people ages 75 and over for Medway up to 2030.

Age Group	2015	2020	2025	2030	%age Increase (2015-2020)	%age Increase (2015-2030)
Age 75-79	7,900	9,100	11,900	11,000	15.19%	39.24%
Age 80-84	5,300	6,300	7,400	9,900	18.87%	86.79%
Age 85-89	3,100	3,600	4,400	5,400	16.13%	74.19%
Age 90 and over	1,700	2,000	2,600	3,500	17.65%	105.88%
Total population 75 and over	18,000	21,000	26,300	29,800	16.67%	65.56%

Table 4: Medway population projections, aged 75 and over projected to 2030, Source: POPPI

In a recent study of multi morbidity by Melzer.et.al (2014), the percentage of 65 to 84 years old people in England with three or more long term conditions was estimated 35.1% (95% CI: 32.9%-37.4%) and for 85+ years old population was estimated 55.1% (95% CI: 52.6%-57.5%)⁶. The table above for Medway shows that by 2020, there will be an increase in the size of population aged 85 and over by 17%, and by 2030 it is showing a vast increase of 85%. Based on the national estimate, it can be predicted that in Medway, by 2020 over 3000 people and by 2030 nearly 4900 people aged 85 and over will be living with three or more long term conditions.

⁶ Melzer, D., Tavakoly, B., Winder, R.E. et al, Much more medicine for the oldest old: Trends in UK electronic clinical records. Age Ageing. 2015;44:46-53.

4.4. Medway's electronic palliative care co-ordination system (EPaCCS) - 'My Wishes Register'

The 'My Wishes' register is an important secure record of how patients wish to be cared for as they approach the end of their life. It ensures people caring for them know what they want.

The process for end of life care coordination in Medway is dependent on 'My Wishes'. This is a formal record of patients' preferred priorities for care and is held by Medway Community Healthcare (MCH). My Wishes is a system wide tool that is used by all professionals including GPs, MCH staff and staff at the acute trust who can view patient preferences held on the system, this is in addition to GP's own palliative care register.

Provider data as reported to Medway CCG shows that in 2015/16, 451 patients were added to the 'My Wishes' register. Of this number, 207 had either confirmed their preferred place of death or were undecided at the time they were asked. 174 of these patients died during the course of the year and of this number, 130 (74%) died in their preferred place of choice. Given that the overall number of deaths in Medway is on average 2,140 per year for the five year period (2010 to 2016), an increase in the number of patients being registered on My Wishes would support health and social care colleagues to make decisions about care provision that reflect the wishes expressed by the patient.

There is clear evidence that the system is not being used consistently which needs to be addressed.

5. Cost-effective commissioning of End of Life care

The National End of Life Care Intelligence Network and Health Economics team in Public Health England have published a number of products to support commissioning decisions for end of life care services. One such product is an *end of life care analytical tool*. This interactive tool is made up of two components. The first provides a summary of the costs, impacts and wider issues associated with different interventions and services for providing care and support for patients at the end of their lives. The second component enables the user to explore the potential trade-offs associated with shifting resources and activity away from secondary care into primary, community and social care settings. The economic tool helps to inform commissioners in their decision-making for end of life care services. It explores the trade-offs between shifting end of life care out of secondary services and describes interventions that might be deployed to achieve such savings.

Table 5 below shows annual cost of number of days spent in Hospitals arising from emergency and non-emergency admissions by the illness category for NHS Medway CCG for the number of deaths between the time periods of 2013-2014.

Illness Category	Number of Deaths	Percentage of Deaths in Hospital	Annual Cost of Number of Days Spent in Hospitals Arising from Emergency and Non-Emergency Admissions
Cancer (ICD10 C00-C97)	651	27%	£3,427,902
Circulatory disease including heart disease and stroke (ICD10 I00-I99)	517	51%	£2,538,984
Respiratory disease (ICD10 J00-J99)	337	65%	£2,102,289
Alzheimers disease and dementia (ICD10 F01, G30, R54)	220	32%	£1,430,498
External Causes (ICD10 V00-Y89 and U509)	80	35%	£241,702
All others (Neo-natal deaths were excluded from the data)	342	67%	£2,177,142
All	2,147		£11,918,517

Source: PHE, Cost-effective commissioning of end of life care (<http://www.yhpho.org.uk/default.aspx?RID=257011>)

Table 5: NHS Medway CCG: The number of deaths in 2013-2014 based on illness category

Taylor and Carter (2004), analysing data from the Marie Curie Nursing Service, estimate £2 savings for each £1 spent on home palliative and supportive care.⁷

6. Inequalities

The evidence suggests that there is inequality in end of life outcomes amongst the UK population. The groups experiencing less favourable outcomes include: older people, those with dementia and learning disabilities, those with non-cancer diagnosis and Black, Asian and Minority Ethnic (BAME) groups. [05]

In Medway, 81.9% of deaths occur in people over the age of 65 with 62.3% of those being in the over 75 age group, suggesting poor access to end of life services for older people. This group have complex needs due to their frailty, co morbidities and increased reliance on support from older carers.

Figure 1 shows the number of deaths from cancer (687), circulatory disease (292) and respiratory disease (207), mental & behavioural (231). A proportion of these groups will also have had dementia. It is estimated that for those over 85, the prevalence of dementia is 21%.[06] This represents a significant group with unmet needs, people whose preferences for end of life care may not have been identified earlier and then provided appropriate support.

⁷ Taylor, D.G. and S. Carter. 2004. Valuing choice – Dying at Home. A Case for Core Equitable Provision of High-Quality Support for People who Wish to Die at Home, UK: Marie Curie Cancer Care.

In 2016, 38.6% of deaths which were not sudden were attributed to cancers in Medway, suggesting a large proportion of patients with non-cancer diagnosis. The majority of these patients are older and frailer than those with cancer and thus requiring more support for longer periods. [07]

Deprivation is a known risk factor for health inequalities and has been identified as a risk indicator for poor end of life care outcomes. [08] Social factors such as deprivation (lower income) increased age, and coming from a minority ethnic descent were associated with fewer home deaths. This may be explained by the lower income and resources available to afford adequate care at home. [09]

6.1. Gaps in terms of Black, Asian and Minority Ethnic groups (BAME) access

The National End of Life Care Strategy highlights that although much has been done, inequalities still exist in the care that different groups of people receive at the end of life. According to 2011 census, population of BAME group is around 10.4% in the Medway.

During 2013, Public Health England published a report called 'Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK'⁸, which provides an evidence-base to understand the profile of BAME populations living in the UK, and identifies their unmet needs regarding palliative and end of life care. The report highlighted that BAME groups had lower access to palliative and end of life care services when compared with white British people. This was associated with lack of awareness of relevant services, lack of information in relevant language and also previous bad experiences when accessing care also contributed to the gap. Poor communication between the healthcare professional providing end of life care and the patient or patient's family also contributed to the inequalities observed by the BAME groups. Lack of referrals to the end of life care services also contributed to the gap.

7. Projected service use and outcomes in 3 to 5 years and 5 to 10 years

It is predicted that by 2020, the ageing population will increase globally, with more people dying from chronic rather than acute diseases [10] and health care will increasingly focus on achieving the best possible quality of life for patients and their families and providing palliative care. Part of this includes meeting their wishes with regards to place of care and of death.

In Medway, it is anticipated that by 2020, there will be an increase in the size of population aged 85 and over by 17%, and by 2030 it is showing a vast increase of 85%. Based on current trends, it is expected that the prevalence of major causes of death in Medway will continue to rise over the next 5 to 10 years. This increase in prevalence and an ageing population will impact on end of life care services within health and social care.

⁸ https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf

8. Services' commissioned that support End of Life care

8.1. Primary Care

General Practitioners (GPs) provide generalist support for end of life patients according to their needs through the dying process in line with the Gold Standards Framework, including pain management, emotional support and coordination of care dependent on the patient and carers needs.

8.2. Community Nursing Service

The Community Nursing Service, provided by Medway Community Health Care, delivers 24/7 nursing services to patients registered with a Medway GP, over the age of 18 years and are either permanently or temporarily housebound. The Service functions as part of an integrated health and social care model and works collaboratively with stakeholders to deliver high quality patient care. Community nursing provides the majority of the palliative and end-of-life patients care for patients living in their own homes or residential care.

8.3. Specialist Palliative Care Services (SPCS)

The SPCS, provided by Medway Community Health Care provides support alongside community nursing for palliative patients over the age of 18 years, who have complex care needs that are difficult to manage such as pain, nausea, vomiting, dyspnoea, constipation, anxiety, and agitation. The service also supports patients, their families and carers who have complex psychological needs including concerns about children, vulnerable individuals, spiritual or religious concerns. This SPCS is made up of several components:

- **Community Palliative Care Team:** The team provides training and advice to support community nursing teams, specialist community teams and GP's to help manage the more complex palliative patients and those presenting in the terminal phase of illness offering holistic advanced care planning and bereavement counselling.
- **Hospital Palliative Care Team:** The team assesses patients known to SPCS should they be admitted to Medway Foundation NHS Trust (MFT) and also accept new referrals from Consultants and senior nurses in the hospital. They provide specialist advice regarding symptom control and advance care planning, and support early discharge to either the patient's own home, care home, Wisdom Hospice, and/or facilitate access to the Day Hospice. The team is supported by a Palliative Care Consultant. The team will also attend specific Multi-Disciplinary Team meetings and support triage of patients admitted to Medway Maritime Hospital's Emergency Department, Intensive Care Unit, and Critical Care Unit.
- **Day Hospice:** The day hospice is based at the Wisdom Hospice and offers families and carers respite, building psychological support and resilience by exploring various methods of developing coping strategies. Patients already known to SPCS can be referred after discussion with Community Palliative Care Nurses and need to be well enough to attend, be able to travel to hospice and agree to participate in therapeutic programmes. A range of therapeutic activities are offered and include art therapy, complementary therapies, carers groups, textiles groups and making memory boxes. The type of activity depends on patient interests' and availability of volunteers to facilitate

the activities, which are supported by a clinician to support conversations and complete advance care planning.

- **Wisdom Hospice Inpatient Unit:** The hospice has 15 beds to support patients known to SPCS and/or community nursing who have complex symptoms or psychosocial and spiritual care needs which are unable to be met, or are difficult to meet in the patient's own home. Referrals can be made by GP, Acute Consultant, Senior Community Nurse or Clinical Nurse Specialist. If a patient is in need of urgent admission but is not known to SPCS a domiciliary visit will be made same day or next day to assess patients' needs.
- **Occupational Health and Physiotherapy:** Occupational health and physiotherapy is for patients known to the SPCS to provide support with assessment for aids to daily living, management of fatigue, non-pharmacological interventions associated with end of life and optimising function.
- **Families and Carer's support team (includes welfare benefits advice):** Offers assessment of complex psychosocial support, counselling, therapeutic support to young children and vulnerable individuals. Patients are able to self-refer or be referred by another professional. This team also includes the Welfare Advice Team which provides support to patients and their families who are known to the service with welfare benefit advice and entitlement, help with accessing housing, social care, advocacy and spiritual support.
- **Bereavement Service:** The bereavement service, provided by Medway Community Health Care, is for families or carers whose relative or friend has died under the care of SPCS and for those relatives who have experienced prolonged or complex reaction to loss.

8.4. Cruse Bereavement care

Provides comprehensive bereavement support to anyone bereaved by providing advice and counselling. The service is available to Medway residents and their immediate family, as well as the extended family and friends at whatever stage following bereavement.

8.5. Medway On Call Care (MedOCC): Palliative Care helpline & Medway's electronic palliative care co-ordination system (EPaCCS)

The palliative care helpline provides access to 24/7 crisis support for end of life patients, their family and / or carers. GPs and nurses are able to provide telephone advice, visit patients, and as appropriate refer to other community and specialist teams.

EPaCCS, known locally as 'My Wishes' ensures that patients are able to record electronically (via their health care worker) their wishes and advance care decision which can then be accessed, respected and acted upon by health and social care professionals. MedOCC also facilitates 24/7 access to South East Coast Ambulance NHS Foundation Trust (SECAMB) crews to 'My Wishes' to support decisions relating to care of palliative / end of life patients.

8.6. Specialist teams in the community

Specialist community services, provided by Medway Community Health Care, include Cardiology, Respiratory, Diabetes, Stroke and Learning Disabilities work in partnership with community nursing and/or the SPCS if their patient is nearing end of life.

8.7. End of Life Facilitators

The End of Life Facilitators, provided through Medway Community Health Care, provide support to all care homes, both nursing and residential in Medway with end of life care provision including advanced care planning, advice to families and carers in enabling residents to die in their own residence.

8.8. Marie Curie night nursing service

This service is accessible via Medway Community Healthcare; it provides care for all palliative patients and their carers who need support at night to enable them to stay in their preferred place of care.

8.9. Specialist Assessments and Placements Team (SAPT)

SAPT are responsible for ensuring the delivery of NHS Continuing Healthcare for the local population on behalf of the Clinical Commissioning Group.

Many people in England have on going care needs as a result of disability, illness or accident, the vast majority get help and support which they have to pay something towards – either through social service charges or because they are assessed as having enough money to buy the care themselves. However for some people the need for nursing and or healthcare support is of such a level/or type that they qualify for all their assessed needs to be met by the NHS, including those personal and social care needs which might otherwise be met by social services or funded by the individual themselves.

To qualify for NHS Continuing Healthcare the individual has to be assessed as having 'Primary Health Need'. Eligibility is not assessed on a particular illness or disability, but whether the individuals 'day to day' nursing/healthcare needs are, when taken as a whole, beyond the local authority (social services) power to meet.

Referrals to SAPT can be made by health and social care practitioners completing the Department of Health 'Checklist Tool' which will indicate if the individual meets the threshold for further assessment of their needs; or, in the case of individuals who have a rapidly deteriorating condition, with limited life expectancy and an increasing level of dependency, health practitioners can refer to SAPT using the 'Fast Track Tool'.

The nurses in SAPT will assess eligibility for NHS Continuing Healthcare and if the individual is eligible will arrange/commission such services to meet the assessed needs. Eligibility is reviewed within three months and then at least annually. If individuals needs change so might their eligibility for NHS Continuing Healthcare.

8.10. Adult Social Care

Adult Social Care, provided by Medway Council, helps people to live as independently as possible by providing coordinated person centred services. This can include home care with

personal and practical support, equipment and adaptations to assist daily living, meals or residential and nursing support. Services provided are wide ranging so anyone can request a needs assessment. Social Workers, Occupational Therapists and Social Care Officers can carry out an assessment of need and plan care accordingly.

8.11. Medway NHS Foundation Trust (MFT) End of Life Care Team

The End of Life Care Team works together with other healthcare professionals (doctors, nurses, occupational therapists, pharmacists etc.) providing a holistic approach to care, including physical, emotional and spiritual support to promote comfort and dignity in the final stages of life.

The team consists of Clinical Nurse Specialists and a Consultant offering end of life care, advice and support for patients in the last hours or days of life, for those identified as important to them and for the ward staff caring for them.

8.12. Other services and support available are;

- **Carers First**, a voluntary and community sector organisation that provides general support and advice to carers, including administration of the Medway Carers Support payment and work within the Integrated Discharge Team (IDT).
- **Agincare**, provides a carers respite breaks service.
- **Medway Council** completes the statutory carers assessments, provide advice and support including arranging packages of care for cared-for or carers-specific. This may be through a direct payment.
- **Care Navigator services**, is a general information and guidance signposting service. A 'one stop shop' where patients, carers, healthcare professionals can go for advice on what support is available in Medway to meet people's holistic care needs. Examples include helping people to access benefits, mobility aids, befriending, dog sitting, and food bank.
- **The Integrated Discharge Team**, is based at Medway Hospital and supports the hospital discharge process for all patients. The service works closely with social services, telehealth, community nursing and the care navigator service. The team employs its own social workers. Staff carry out daily ward rounds where they attend 'board meetings' and review patient case notes to see if there are any patients who they can support to enable early supported discharge.

9. Key issues and gaps identified with current provision

- As a society we do not talk openly about death and dying. Relatively few adults, including older adults, have discussed their own preferences for care with a close relative or friend, making it difficult for others, family and professionals, to help ensure their wishes are met.
- Only one third of patients that had expected deaths in 2016/17 had their wishes recorded
- Equipment provision has been found to be complicated for patients when doctors are across boundaries as different suppliers of equipment have conflicting processes.
- There is a lack of sharing of information across the whole system which has proven limitations to patient care.

- Co-ordination of care and communication between existing end of life care providers is inadequate and needs to be addressed.
- There is a lack of consistent understanding of the NHS Continuing Healthcare criteria and processes that should be followed including when circumstances change and a review may be indicated earlier than three months.
- The lack of urgent non-medical support means that patients can be admitted to hospital when rapid access to support could have prevented this.
- The needs of those with complex physical, learning or mental disabilities may not be identified, resulting in inadequate care at end of life. For example, people with dementia may not be referred for specialist end of life care and specialists in end of life care are more used to dealing with conditions with a steep period of decline, such as cancer, rather than the more uncertain prognosis of dementia. This may be, in part, because dementia is not generally recognised as a terminal condition.
- People frequently need care from multiple services and they need or want to transfer between locations (home, care home, hospital and hospices) and geographies. Care provision is often not well coordinated.
- Services in the community are sometimes unable to respond to these needs because of capacity limits, resource constraints or inadequate training resulting in people being admitted to hospital as an emergency rather than being cared for in their normal place of residence (home or care home).
- The majority of people in England would prefer to die at home, however lack of timely access to appropriate community services prevents more people dying in their place of choice. In Medway, nearly half of the deaths (48.2%) occur in hospital.
- In Medway, It is estimated that the age group 75 or above will see a rise in population of 17% from 2015 to 2020. The projected increase of the ageing population in Medway points to the future needs in developing skills in the community if admissions, especially, emergency admissions are to be avoided.
- After someone has died expectedly, problems may arise with not having a clear process in place and staff not being trained to ensure timely verification and certification of death. This may lead to unnecessary involvement of the coroner or police which can add to the distress of the bereaved.
- The main barrier to the delivery of good quality end of life care is because people are not identified early enough to provide this care as they are approaching end of life. In 2015/16, 554 people were on the General Practice Palliative Care register, implying poor identification of patients with end of life care needs especially non cancer patients.
- Medway electronic palliative care system is an important secure record of how patients wish to be cared for as they approach end of their life and it is not being used consistently.
- There is no existing mechanism for identifying the needs, wishes and preferences for end of life care for people with Learning disabilities and Dementia.
- A gap has been identified in pre bereavement, patient and carers that come under the specialist palliative care service receive pre bereavement but other end of life care patients does not receive this service.
- Lack of training and support for staff to ensure good end of life care is provided in all residential and care homes.

- Lack of information and data to inform decisions regarding the end of life care needs specific to black and ethnic minority groups, including spiritual and cultural needs.

10. The future of End of Life Care in Medway

The analysis and engagement undertaken to develop this strategy identifies that there are already a good range of end of life care services for adults within Medway however; it also identifies variation in availability and understanding of services from both the public and health care professionals perspective. It is clear that there is not a universal offer of end of life care to all patients. The analysis has identified key issues and gaps which reflects the national situation that existing services do not meet the current needs of the population.

Who was involved in developing the strategy?

The NHS has a clear mandate from the Government to take action to improve end of life care, and that begins with a conversation about what 'good' looks like. Discussions with our local stakeholders including patients, carers, patient, health and social care professionals, GPs and commissioners have helped us to define locally our overarching aim and the key priorities.

The strategy has been developed jointly with Swale Clinical Commissioning Group to ensure consistency in approach as both Swale and Medway local Acute Trust is Medway NHS Foundation Trust (MFT) and specialist palliative care services are both commissioned in the community through Medway Community Healthcare (MCH).

How was the strategy developed?

Providing the opportunity of a good death lies at the heart of this document; by working collaboratively with our local stakeholders including patients, carers, and a wide range of health and social care professionals. We have identified our local priorities by using the six national ambitions for end of life care as a framework.

Key Priorities to deliver the strategy

Key priorities have been formulated in the development of this strategy to deliver our local vision. These are set out below and include implementation activities for each priority.

10.1. Priority One: Ensure professionals are supported to provide care

There is widespread agreement on the importance of workforce development to the overall success of this strategy. Clinical and non-clinical health and social care professionals at all levels will be provided with the necessary education and training to enable them to identify patients in the last year of their life and provide high quality end of life care including those who do not die from cancer.

Promoting consistency of skills and messages will ensure professionals feel confident in their own ability to hold honest and well informed conversations about dying, death and bereavement. It will also help patients, carers and families to have clear expectations.

Implementation actions:

- To develop a multi-agency approach to training and education that promotes consistency for professionals across all end of life pathways, and where appropriate is collaborative. This will range from specialist end of life staff to key front line staff that require more general training, including staff in care homes. This will include a full review of current arrangements looking at opportunities to share training and education resources, looking to introduce training as mandatory including e-learning, identifying training opportunities that exist across Kent and through our neighboring counties. The objective is to increase knowledge and confidence, including of the Gold Standards Framework (GSF) Advance Care Planning, do not attempt cardio pulmonary resuscitation (DNACPR), and verification of death. It will also include strengthening our links with Health Education England to identify opportunities to support our local education and training plans.
- To develop a knowledgeable and competent workforce that is consistently trained in aspects of end of life care that is appropriate to their role and setting, a review of local competency frameworks across organisations will be undertaken to develop a standardised competency framework across all levels of professionals. This will be aligned with the end of life care core skills education and training framework published in 2017 which was commissioned and funded by Health Education England and developed in collaboration with Skills for Health and Skills for Care.
- To improve signposting and knowledge of the available services and tools to enhance professional awareness. The “Map of Medicine” system (An information and decision making tool for primary care) will be updated to ensure that GPs have access to current pathways and service provision, for all other health and social care professionals options will be reviewed to reach an agreement on the best approach.

10.2. Priority Two: Developing a new model of care to deliver high quality services to support patient choice

There is widespread agreement on the importance of ensuring that patients are supported to achieve their preferred place of death ensuring that there is a consistent approach for all irrespective of place in which someone is dying: hospital, hospice, own or other home and during transfers between different settings.

Evidence suggests that more patients preferred place of death is in their own home yet locally, the majority of patients are dying in a hospital setting. Our end of life model will be redesigned to ensure that there is a coordinated and universal offer of end of life care to all patients that supports their choice. At a time when there are constraints on NHS spending, resources within the existing model may need to be realigned to meet patients’ preferred place of death whilst ensuring that services provide good quality of care and value for money.

Implementation actions:

- To work collaboratively with health and social care professionals to review our current model of care to improve integrated working including standardising the approach.
- A task and finish group of key providers and stakeholders will be established to review and make recommendations to redesign our current end of life model of care that will meet the needs of our local population as identified within the needs assessment. Although not exhaustive, this will include ensuring that the estate is fit for purpose to support a new model for end of life care, reviewing end of life national policy including NICE and best practice models. It will specifically include addressing the needs of underrepresented groups including patients and carers from ethnic minority backgrounds, people with learning disabilities, dementia, and people from the lesbian, gay, bisexual and transgender community and the homeless.
- To maintain an up to date end of life needs assessment that is regularly reviewed to ensure that our local services and resources reflects the needs of our population.

10.3. Priority Three: Developing and improving systems to support consistent, efficient and effective care

People's individual's needs, priorities and preferences for end of life care need to be identified, documented, reviewed, respected and acted upon wherever possible. Where patients are identified early their wishes are recorded which means any professional coming into contact with that person will have a clear plan to follow which in turn means patients, carers and families are supported throughout the end of life journey.

There is a recognition that whilst a new end of life care model needs to be developed, a focus on current logistics is also required to ensure that individuals have access to support that avoids unnecessary admission to hospital or delay in returning home.

Implementation actions:

- To design and implement a single Advance Care Plan (ACP) to record patient's plans and wishes and priorities for their care in the future. To ensure that the ACP is then maintained and shared on our electronic palliative care co-ordination system (EPaCCS), known locally as My Wishes.
- To undertake a review of EPaCCS, locally known as My Wishes, to meet with local requirements. A protocol will be developed to relaunch our system and to improve co-ordination and consistency of use including who should have access to the data, the information that should be recorded, how it is collected, updated and quality assured. This will include reviewing the links with the South East Coast Ambulance Service NHS Foundation Trust (SECAmb) Intelligence Based Information System (IBIS) which identifies end of life patients to ambulance crews and enables them to access patients preferences.

- To ensure GPs are informed of the services available and the support that they can receive in managing palliative care patients and carers. To ensure that patients are identified early and are recorded on the GP system as palliative care and promote consistency of coding.
- To actively share data and information across organisations to provide a whole system view of end of life care. To develop a set of whole system measures that is regularly shared to measure our improvements.
- To increase awareness and actively promote the 24/7 palliative care line and have clear processes supporting the use of this service by completing an out of hour's feasibility study for palliative care calls.
- To review and improve the timeliness of transfers of care and from the Acute Hospital into the community including Continuing Healthcare funding, and from children's service to adult services.
- Access to anticipatory medication to be defined in and out of hours and awareness of this to be increased.

10.4. Priority Four: Ensuring that patients, carers and families feel supported

To ensure that people are treated with dignity and respect at the end of their lives, through ensuring that patients, their carers and their families are informed and are able to easily access to support and care that meets their needs irrespective background, race, and religion.

Implementation actions:

- To develop booklets that provide information to both patients and carers to ensure that they have a better understanding of the help that is available, how they access it and what to expect as the end of life approaches.
- To ensure that services provide care for all elements of distress: physical, emotional, social and spiritual to all patients and carers. Engagement and development of partnerships with third sector organisations and local communities will help to identify ways to incorporate spiritual and cultural needs into local care.
- To engage with local communities to address the needs of underrepresented groups including patients and carers from ethnic minority backgrounds, people with learning disabilities, dementia, and people from the lesbian, gay, bisexual and transgender community, the homeless and gypsy and travelling communities.
- To undertake a review of bereavement care including identifying opportunities that exist within the voluntary and charitable sector, and local communities to provide care for all end of life patients. This includes approaches to introducing pre bereavement support to ensure that carers and families are appropriately supported both during a patient's life

and after death in all care settings. It also includes identifying opportunities that exist within the local community will support local health and social care services at a time when there are constraints on current spending.

- To ensure that relatives or carers who might be vulnerable and at risk of social isolation following the death of a loved one are identified and signposted /supported appropriately through bereavement. This aligns with the Medway Social Isolation Strategy and Action plan (2014-18) which is currently being revised.
- To actively seek the views of patients nearing end of life, and families and carers with recent experiences of death, dying and bereavement to locally understand access and quality ensuring services are reflective of their needs.

10.5. Priority Five: To promote local awareness of death, dying and bereavement

Talking about dying makes it more likely that patients will die as they might have wished and it will make it easier for families and carers if they know their loved one has had a 'good death'. Talking more openly about dying, death and bereavement, will help to increase awareness that patients can make plans for the end of their life to die where or how they would wish. Our aim is to increase awareness within Medway through promoting end of life care using consistent messages and engaging with the local community to improve public awareness and the importance of discussing death and dying.

Implementation actions:

- Develop a Whole System End of Life communications plan that is annually refreshed to identify opportunities to actively promote end of life care at key events across Medway including Dying Matter week.
- To establish an approach to actively engaging patients, families and their carers to ensure their views shape changes in end of life care.
- To work with key partners locally to develop an approach to share good practice, promote achievements, build on the engagement with our local health and social care professionals and improve networking across local communities and voluntary and charitable sectors. This will also include inputting into and engaging with existing networks nationally and across the South East.
- To look at innovative ways of engaging with and encouraging the local communities to talk openly and plan for death.

11. Implementing our vision

An End of Life Programme Board was established to provide direction and oversight to the development and delivery of an end of life strategy. This Board has representation from key partners and stakeholders from across both Medway and Swale and is chaired by our Clinical Lead for End of Life Care. This Board will remain in place to continue provide leadership and assurance of delivery of the local vision for end of life care.

11.1. Measures of Success

Outcome measures will be used to monitor and evaluate the impact of the delivery of the key priorities identified within this strategy. The table below sets out key outcome measures; work will continue with partners to further develop outcome measures as key actions to implement the strategy progresses and to ensure alignment with best practice and national guidance as these become available. All outcome measures will be reviewed and reassessed as the target date for each is reached.

Outcome Measure	Links to Ambitions for EoL care
By March 2018, agree a schedule of training requirements for all staff directly involved in the identification and provision of end of life Care across whole system (Primary, secondary, community, residential, nursing and domiciliary), and establish target for training within each staff group.	4,5
By October 2017, all organisations to share data to support the implementation of whole system monitoring of key services and outcome measures.	5
By March 2018, agree a new end of life model of care (including bereavement care) with agreed timeline for delivery.	2,3,4,5
By March 2018, increase the number patients' wishes recorded on the electronic palliative care register to 50%. <i>(In July 2017, there were 24% in Medway.</i>	1,2,4
By March 2019, increase the number of expected deaths with patients' wishes recorded on the electronic palliative care register to 75%.	1,2,4
By March 2019, through earlier identification increase the average length of time that patient spend on the electronic palliative care register from registration to death. Baseline to be established by March 2018, and target to be agreed.	1,2,3,4,5
By March 2019, to reduce the average length of stay in hospital for those identified as end of life following an unplanned admission. Baseline to be established.	3,4

Outcome Measure	Links to Ambitions for EoL care
By December 2017, establish the number of cancer and non-cancer patients that are referred to the palliative care team, and establish targets to March 2020.	1,2
By December 2017, 95% of respondents (professionals, patients and carers) to the localised end of life booklets found they had a positive impact on the dying process.	1, 2, 3, 6
By March 2019, reduce the percentage of deaths in hospital following unplanned admissions by 10%. <i>Deaths in hospital for unplanned admissions in 2015/16 is 48.2%.</i>	2,6
By March 2019, demonstrate an increase in engagement and involvement of local communities and religious leaders, including attendance at the annual conference.	6
By March 2018, increase the quality of care provided and ensure care is appropriate to individual preferences through annual audit of Advance Care Plans.	1,2,3,5

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