End of life

# Summary

End-of-life care helps people with advanced, progressive, incurable illness and the elderly live as well as possible until they die. It includes care provided in the last year of life, e.g. pain management and control of other symptoms, as well as provision of social, psychological, spiritual and practical support for patients and their carers. 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. Care can be provided in all settings (home, residential and nursing care homes, acute hospital, community hospitals, hospices, prisons and any other institutions).[1][2]

People approaching end-of-life often have complex needs, requiring support from different agencies in various locations. The National End-of-Life Care Strategy indicates that the majority of people would prefer to die at home.[2] In 2016, there were 2,142 deaths in Medway, of which 47.6% (1020) occurred in hospital, 24.7% (529) at home and 10.4% (222) in care homes. The national strategy highlights the opportunities for health and social care systems to work together to provide coordinated care and support; opportunity for patients to discuss their personal needs; choice of where to be cared for and to die; and appropriate advice and support for carers at every stage.

## Key issues and gaps

* In 2015/16, only 554 people in Medway were on the General Practice palliative care register, implying poor identification of patients with end-of-life care. Identification is known to be worse in non-cancer patients.
* 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, but it is not being used consistently.
* 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%) occur in hospital.
* There is no existing mechanism for identifying the needs, wishes and preferences for end-of-life care for people with learning disabilities and dementia.
* In Medway, it is estimated that the number of people aged 85 or above will rise by 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, in particular emergency admissions, are to be avoided.
* Patients and carers that come under the specialist palliative care service receive pre-bereavement but other end-of-life care patients do not receive this service.
* There is a lack of training and support for staff to ensure good end-of-life care is provided in all residential and care homes.
* There is a lack of information and data to inform decisions regarding the end-of-life care needs specific to black and minority ethnic groups, including spiritual and cultural needs.
* Coordination of care and communication between existing end-of-life care providers is inadequate and needs to be addressed.

## Recommendations for commissioning

* Encourage the use of the Gold Standard Framework’s (GSF) Prognostic Indicator Guidance in primary care to ensure early identification of people approaching the end stages of their disease.
* Medway CCG needs to encourage the GP/primary care team to work closely with other professionals in hospitals, hospices and specialist teams to help to provide the highest standard of care possible for patients and their families.
* Given the generally ageing population and the likely increase over time in percentage of people over the age of 75 from a Black, Asian and minority ethnic (BAME) background, it is recommended that Medway CCG looks at their demographic projections and works accordingly with their clinicians, community groups and SPCS to develop, fund and evaluate appropriate, cost-effective services.
* A gap has been identified in pre-bereavement in Medway. Commissioners should consider the provision of the service through a suitable provider or developing alternative models for providing this service.
* Continued commitment is needed to provide high quality care to enable people in Medway to die in the place of their choice.
* Ensure workforce development (training and education) around the core competencies as outlined in the End-of-Life Strategy: Assessment of needs and preferences, communication, advanced care planning and symptom management.
* Encourage joint working and shared resources across all providers, with an identified lead provider coordinating all services that support the end-of-life pathway.
* Support the development of a single point of access to services to improve the coordination of end-of-life services.
* Voluntary sector organisations should be involved appropriately, especially around issues relating to culture and religion.
* Disseminate information on integrated health and social care end-of-life teams to the public, to ensure timely access to continue care funding.
* Develop a shared IT system to facilitate a more streamlined service through data sharing.

# 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 a hospital stay.[3] In Medway, this equates to about 408 people annually. The report suggests that people approaching end-of-life and their families may be at risk of a poor end-of-life experience if their needs are not being met because they are in an inappropriate setting at the time and therefore not receiving the right and appropriate level of care and support. Early recognition of end-of-life is particularly problematic for patients with non-cancer diagnosis as, traditionally, end-of-life services have been provided to only cancer patients.

## Inequalities

The national End-of-Life Care Strategy highlights that, although much has been done already, inequalities still exist in the care that different groups of people receive at the end of their life.[2] The groups experiencing less favourable outcomes include: older people, those with dementia and learning disabilities, those with non-cancer diagnosis and black and minority ethnic (BME) groups.[4] Deprivation is a known risk factor for health inequalities and has been identified as a risk indicator for poor end-of-life care outcomes.[5]

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 in Medway. Older patients have complex needs due to their frailty, comorbidities and increased reliance on support from older carers. It is estimated that, for those over 85, the prevalence of dementia is 21%.[6] 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.

According to the 2011 census, the BME group is around 10.4% of the Medway population.[7] During 2013, Public Health England published a report called ‘Palliative and end-of-life care for Black, Asian and Minority Ethnic (BAME) 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 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.

In 2016, only 38.6% of non-sudden deaths were attributed to cancers in Medway, suggesting a large proportion of patients with non-cancer diagnosis. The majority of deaths not attributable to cancer are in patients who are older and frailer than those with cancer and thus requiring more support for longer periods.[9]

Social factors such as deprivation (lower income), increased age, and coming from a minority ethnic descent, were also associated with fewer home deaths. This may be explained by the lower income and resources available to afford adequate care at home.[10]

# The level of need in the population

The majority of deaths (n = 1778) in 2016, were predictable (i.e. non-sudden (see definition below), occurring following a period of chronic illness), where deaths could have been anticipated and care properly planned.

Definition of sudden deaths: Sudden deaths are defined as those occurring due to the following causes: acute myocardial infarction; pulmonary embolism; aneurysm of pulmonary artery; sudden cardiac death; cerebrovascular diseases; aortic aneurysm and dissection; influenza and pneumonia; other acute lower respiratory infections; suppurative and necrotic conditions of lower respiratory tract; other diseases of the pleura; post-procedural respiratory disorders; respiratory failure; injury, poisoning and certain other consequences of external causes; external causes of morbidity and mortality.

Table 1 shows that the proportion of non-sudden deaths has increased over the last 10 years, implying that the number of people in Medway who could benefit from end-of-life care is increasing.

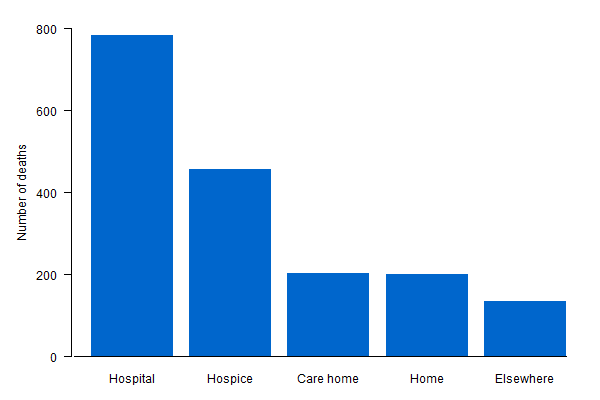
**Table 1.** Total number of deaths and proportion of non-sudden deaths in Medway 2007-2016 [11]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Year | Sudden death | Non-sudden death | Total number of deaths | % non-sudden death |
| 2007 | 414 | 1,455 | 1,869 | 77.8 |
| 2008 | 495 | 1,615 | 2,110 | 76.5 |
| 2009 | 396 | 1,613 | 2,009 | 80.3 |
| 2010 | 391 | 1,698 | 2,089 | 81.3 |
| 2011 | 404 | 1,607 | 2,011 | 79.9 |
| 2012 | 400 | 1,730 | 2,130 | 81.2 |
| 2013 | 378 | 1,693 | 2,071 | 81.7 |
| 2014 | 421 | 1,806 | 2,227 | 81.1 |
| 2015 | 421 | 1,892 | 2,313 | 81.8 |
| 2016 | 364 | 1,778 | 2,142 | 83.0 |

In 2016, the four main underlying causes of non-sudden death in Medway were: cancers (neoplasms) - 687 deaths (38.6%); circulatory diseases - 292 deaths (16.4%); mental and 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.

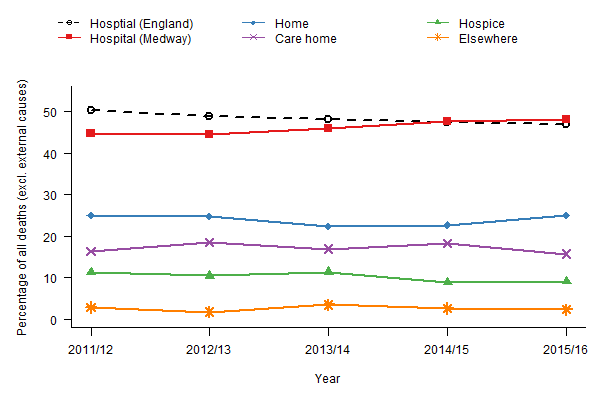
## Place of death

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 carers.[12] Figure 1 shows the place of death recorded for Medway residents in 2016 for non-sudden deaths (hospital includes deaths in an acute or community hospital, not psychiatric).[11]



**Figure 1:** Place of death (non-sudden) [11]

Figure 2 shows that in Medway, the proportion of deaths in hospital has risen from 44.7% in 2011/12 to 47.0% in 2015/16 (hospital deaths include deaths occurring in a community hospital) while in England during the same period, the proportion of deaths in hospital has fallen from 50.4% to 48.2%. The proportion of deaths occurring at people’s homes in this time frame has stayed approximately the same at around 25% for Medway, however the proportion of deaths occurring in a hospice or care home has decreased. This suggests further work is still needed to ensure equality in access to services for all relevant conditions.



**Figure 2:** Trends in place of death in Medway [12]

# Current services in relation to need

## Palliative Care Register

There are about 2000 deaths per year within the Medway area. It is recognised that the number of deaths per year is about 1% of a GP practice caseload and there is a national campaign to encourage GPs to identify these patients called [Find Your 1%](https://www.dyingmatters.org/gp). A register of palliative care patients is held within GP practices. In 2015/16, 554 people in Medway were on the General Practice palliative care register.[13] Patients on this register should be reviewed on a 3-monthly basis by the practice health care team. A DS 1500 form 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. The DS 1500 is a form used by GPs in the UK allowing the immediate release of funds to aid a patient with a terminal illness. 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. A well-maintained register of patients who are approaching the end of life is a tool to allow for better care planning and coordination.

## ‘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). GPs, MCH and staff at the acute trust can view patient preferences held on ‘My Wishes’. However, ambulance staff are required to telephone the out-of-hours service in order to access the same information.

Provider data, as reported to the 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. Overall, 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 2010-2016, an increase in the number of patients on the ‘My Wishes’ register would support health and social care colleagues to make decisions about care provision that reflect the wishes expressed by the patient.

## Primary Care

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

The Palliative Care Helpline is in place to provide patients at the end of life, including their carers and family, access to 24/7 crisis support. GPs and nurses consult, visit patients, provide telephone advice, and refer to community and specialist teams where appropriate.

## 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 who are 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 care for patients living in their own homes or residential care.

## Secondary Palliative Care Service

The Secondary Palliative Care Service is provided by Medway Community Health Care. This service provides support alongside community nursing to palliative care 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 or vulnerable individuals, and spiritual or religious concerns.

For a detailed breakdown of the components of the Secondary Palliative Care Service, and other services that support end of life care, please refer to [Medway’s End of Life Care Strategy for Adults 2017-2020](https://democracy.medway.gov.uk/mgconvert2pdf.aspx?id=38570).

# Projected service use and outcomes

It is predicted that by 2020, the ageing population will increase globally, with more people dying from chronic rather than acute diseases[14] 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. Population projections for Medway from 2015 suggest that by 2020, there will be an increase in the size of population aged 85 and over by 17% to 5,600, and by 2030 it will increase by 85% to 8,900.[15] 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 have an impact on end-of-life care services within health and social care.

In a study of multimorbidity by Melzer et al. (2015), the percentage of the population in England aged over 85 years with three or more long-term conditions was estimated at 55.1% (95% CI: 52.6%-57.5%).[16] Based on the national estimate, it can be predicted that in Medway, by 2020 over 3,000 people and by 2030 nearly 4,900 people aged 85 and over will be living with three or more long-term conditions.

# Evidence of what works

* The National [Gold Standard Framework] (<http://www.goldstandardsframework.org.uk/>) (GSF) aims to support best implementation of the GSF in all settings, using a common framework and toolkit of resources so that generalist frontline staff can provide quality of care for people nearing end-of-life, whatever their illness and wherever the setting.
* Department of Health [End of life Care Strategy: quality markers and measures for end of life care](http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681). DH. London. (2009)
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* [Capacity, care planning and advance care planning in life limiting illness](http://webarchive.nationalarchives.gov.uk/20150317164525/http://www.nhsiq.nhs.uk/resource-search/publications/eolc-ccp-and-acp.aspx). A Guide for Health and Social Care staff (2012, revised 2014)
* [The Preferred Priorities of Care, National End of Life Programme](http://webarchive.nationalarchives.gov.uk/20160805140336/http://www.nhsiq.nhs.uk/resource-search/publications/eolc-ppc.aspx) (2011)
* [The National Carers Strategy](https://www.gov.uk/government/publications/the-national-carers-strategy) emphasises the need for mental wellbeing and support for carers. (2008)

# Unmet needs and service gaps

* More training is required for the wider workforce on end-of-life care. Need to educate professionals to initiate end-of-life conversations and advance care planning.
* There is a need for a proactive identification of people approaching end-of-life, better coordination of care and communication between services.
* There is inequity in end-of-life care for non-cancer patients especially those with mental health problems e.g. dementia and patients with long-term conditions and learning disabilities.
* There is a gap in pre bereavement, only patients with complex needs receive the service.
* The majority of people in England would prefer to die at home, however lack of timely access to appropriate community services prevent more people dying in their place of choice. In Medway, nearly half of the deaths (48%) occur in hospital.
* There is no existing mechanism for identifying the needs, wishes and preferences for end-of-life care for people with dementia and learning disabilities.
* There is currently no systematic approach to capturing patients’ views in the use of the service, although there is patient representation within the End-of-Life Care Group.
* 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.
* The projected increase in 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.
* Lack of information and data to inform decisions regarding the end-of-life care needs specific to BME groups, including spiritual and cultural needs.

# Recommendations for commissioning

* Encourage the use of the Gold Standard Framework’s (GSF) Prognostic Indicator Guidance in primary care to ensure early identification of people approaching the end stages of their disease.
* Medway CCG needs to encourage the GP/primary care team to work closely with other professionals in hospitals, hospices and specialist teams to help to provide the highest standard of care possible for patients and their families.
* Given the generally ageing population and the likely increase over time in percentage of people over the age of 75 from a Black, Asian and minority ethnic (BAME) background, it is recommended that Medway CCG looks at their demographic projections and works accordingly with their clinicians, community groups and secondary palliative care services to develop, fund and evaluate appropriate, cost-effective services.
* There should be a standardised advance care plan, which can be used across whole system and to be recognised and staff supported.
* A gap has been identified in pre-bereavement in Medway. Commissioners should consider the provision of the service through a suitable provider or developing alternative models for providing this service.
* Continued commitment is needed to provide high quality care to enable people in Medway to die in the place of their choice.
* Use local population data available from National End-of-Life Intelligence Network, Hospital Episode Statistics, QOF and end-of-life care analytical tool which is published by Public Health England.
* Ensure workforce development (training and education) around the core competencies as outlined in the End-of-Life Strategy: Assessment of needs and preferences, communication, advanced care planning and symptom management.
* Encourage joint working and shared resources across all providers, with an identified lead provider coordinating all services that support the end-of-life pathway.
* Support the development of a single point of access to services to improve the coordination of end-of-life services.
* Voluntary sector organisations should be involved appropriately, especially around issues relating to culture and religion.
* Disseminate information on integrated health and social care end-of-life teams to the public, to ensure timely access to continue care funding.
* Develop a shared IT system to facilitate a more streamlined service through data sharing.

# Recommendations for needs assessment work

Review of patients’ place of death, cause of death and their preferred place of death in Medway.

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