# End of life briefing

## Contents

Nearly every person will require End of Life Care (EoLC). It is the care given to a person in the last hours, days, months or years of their life. It is particularly important to consider because the Coronavirus Pandemic has changed the state of healthcare today. It has not only changed what people die from but also the way that people die, and where people die. In order to understand the needs relating to EoLC, it is important to look at the state of end of life care in England and then compare this with the local East Sussex picture. This briefing will focus on current local and national mortality statistics in comparison with recent years.

# What is end of life care?

According to the NHS website, 'end of life care should begin when you need it.' and is likely to cover people in the circumstances below:[1]

> "People are considered to be approaching the end of life when they are likely to die within the next 12 months, although this is not always possible to predict. This includes people whose death is imminent, 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-this includes adults and children and young people born with life limiting conditions
> - have a life-threatening acute condition caused by a sudden catastrophic event, such as an accident or a stroke."

End of life care involves (but is not limited to):

- Recognition that a person might be coming to the end of their life
- Advance care planning
- Palliative care
    - Physical needs for example symptom or pain control
    - Psychological needs for example counselling
    - Religious/spiritual needs
- Preferred place of death
- Financial needs
- Family/friends needs for example for bereavement counselling

[1] NHS 'What end of life care involves' https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/ Accessed 15/7/21

Many healthcare professionals may be involved in palliative and end of life care. These include: GPs, community nurses, palliative care specialist nurses or doctors, occupational therapists, physiotherapists, hospital staff, counsellors, and chaplains.[2]

Palliative care is an important part of end of life care, although there is a crucial difference between the two. Palliative care means the easing of suffering (*palliare* meaning 'to cloak' in Latin)- the improvement of quality of life for patients and their families when someone has a complex or serious disease. Palliative care also has a large role to play when someone is not actively dying. Certain aspects of end-of-life care will not always focus on easing suffering, and are more practical in their aims. *The first step of end of life care is recognising that a person is dying.*

## Advance Care Planning

Advance Care Planning is an essential part of End of Life Care and facilitated/ organised by NHS staff. It is a process of 'enabling individuals to define goals and preferences for future medical treatment and care, to discuss these with family and healthcare providers, and to record and review these preferences if appropriate'. People who are coming to the end of their natural lives may lack the necessary communication skills or cognition to advocate for themselves.[3] There are many areas in which people might choose to express prior wishes, for example:

- Preferred place of death
- Preference for CPR/ITU admission/ventilatory support
- Hospital admission in general
- Which medical treatments are acceptable or not acceptable to an individual e.g. surgery, intravenous medicines, catheterisation, nasogastric feeding
- Whether an individual would prefer a focus on life-sustaining treatment or symptomatic treatment

# Why end of life care is important

## National strategic picture

In 2008 the Department of Health published the 'End of Life Care Strategy' which highlighted the importance of end of life care in England. It emphasised the idea that '*how we care for the dying is an indicator of how we care for all sick and vulnerable*

[2] Ibid

[3] Rietjens J.A.C. et al 'Definition and recommendations for advance care planning: an international consensus supported by the European association for palliative care' *Lancet Oncol.* 2017; **18**: e543-e551

*people. It is a measure of society as a whole and it is a litmus test for health and social care services.*'[4]

'Our commitment to you for end of life care' (2016), and 'The NHS Long Term Plan for England' (2019) have followed.

The NHS's 'Ambitions for Palliative and End of Life Care 2015-2020' framework sets out the following goals:[5]

- Each person to be seen as an individual
- Each person to get fair access to care
- Maximising comfort and wellbeing
- Care is co-ordinated
- All staff are prepared to care
- Each community is prepared to help

The importance of a 'good death' is increasingly accepted as something to aspire towards. Definitions of a 'good death' will be different for everyone, but for many the concept involves:

- Being treated as an individual, with dignity and respect
- Being without pain and other unpleasant symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.[6]

The psychological impact on friends, family, carers, and healthcare professionals cannot be overstated. As Dame Cicely Saunders put it, 'how we die remains in the memory of those who live on'. Good end of life care matters for everyone involved in a person's death. Nobody should have to watch their friends and loved ones needlessly suffer. Healthcare professionals looking after dying people should feel they have the time and the resources that they need to ease suffering, and help people die 'a good death'.

Compelling arguments have been put forward by those in the palliative care sector as to why end of life care needs to be prioritised now more than ever.[7]

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[4] Department of Health 'End of Life Care Strategy' (July 2008) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf Accessed 15/7/21

[5] National Palliative and End of Life Care Partnership 'Ambitions for Palliative and End of Life care: a national framework for local action 2015-2020' (2015) http://endoflifecareambitions.org.uk/

[6] Department of Health 'End of Life Care Strategy' (July 2008) (n3)

[7] Thomas C (2021 *The state of end of life care: Building back better after Covid-19,* IPPR. http://www.ippr.org/research/publications/the-state-of-end-of-life-care

## Inequalities in End of Life Care

There are two dimensions of inequalities relating to mortality – some groups of people die at a younger age than others (variation in life expectancy); and some groups of people who are approaching the end of life are less likely to get good quality end of life care than others. It is the latter inequality which is within the scope of an end of life care strategy. New analysis highlights inequalities and areas for potential improvement in end of life care.[8]

• Acute-led: Despite evidence that it is not optimal, inpatient acute care remains dominant, accounting for £6 in every £10 spent on end of life care.

• Unequal: Despite spending more time in hospitals, normally a more expensive setting, people in the most deprived parts of the country are getting £400 less healthcare investment per person in their last year of life.

• Variable: The shift to a more primary/community-led end of life care model is happening unequally across the country. The South Central Region has a practice care model, which spends 20 per cent less per person – money which can be reinvested in healthcare.

• Workforce: Qualitative work with carers shows continued variation in quality of communication between health and social care professionals and dying people.

## Ageing and mortality

Throughout the UK, people are living longer, with more co-morbidities and living more years in a state of frailty. People's state of health is becoming increasingly complicated.[9] More people will meet the definition of being unlikely to survive for 12 months or more – even though some might live for a number of years.

Public Health England has released provisional estimates of life expectancy at birth for 2020 to show the impact of the COVID-19 pandemic in England and its regions.[10]

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[8] Imperial College London: https://www.imperial.ac.uk/centre-for-health-policy/our-work/end-of-life-care/

[9] Tran J et al (2018) 'Patterns and temporal trends of comorbidity among adult patients with incident cardiovascular disease in the UK between 2000 and 2014: A population-based cohort study', *PLOS Medicine*. https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002513

[10] The estimates for 2020 are the average number of years a newborn baby would live if they experienced the national (or regional) age-specific mortality rates for 2020 throughout their life.

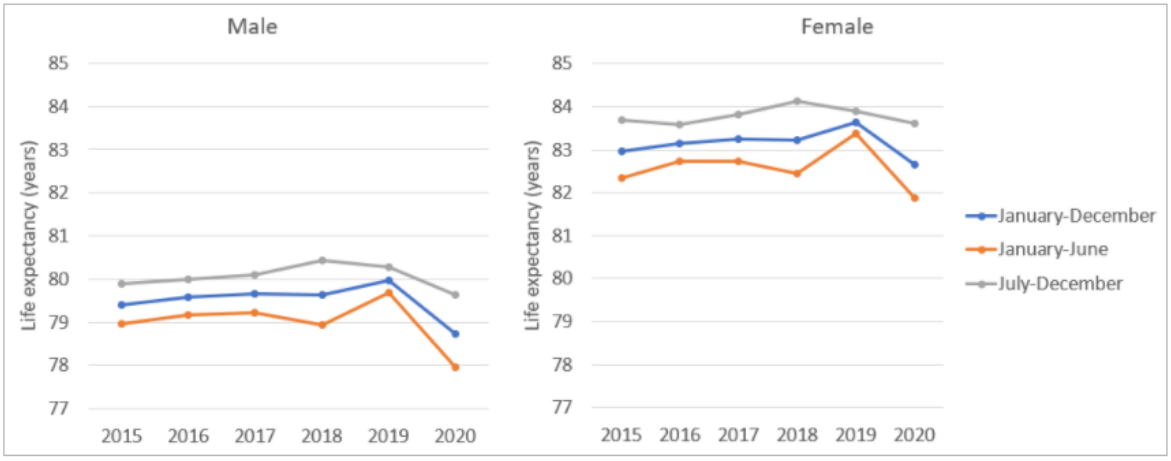
As mortality rates will change in the future, the figures are not a forecast of future life expectancy but provide instead a snapshot of current mortality rates. Life expectancy estimates are an alternative way of presenting mortality rates in order to show the impact of COVID-19 on levels of mortality, and inequality in mortality, in 2020

Life expectancy fell in 2020. Compared with 2019, life expectancy in England in 2020 was 1.3 years lower for males and 0.9 years lower for females. These falls exceed any previous year-on-year changes seen since records began in 1981.

Estimates for the first six months of 2020, covering most of the first wave of the pandemic, show even bigger falls in life expectancy but the estimates for the second half of the year were closer to those in 2019, Figure 1.

There are now also life expectancy data available at District and Borough level.

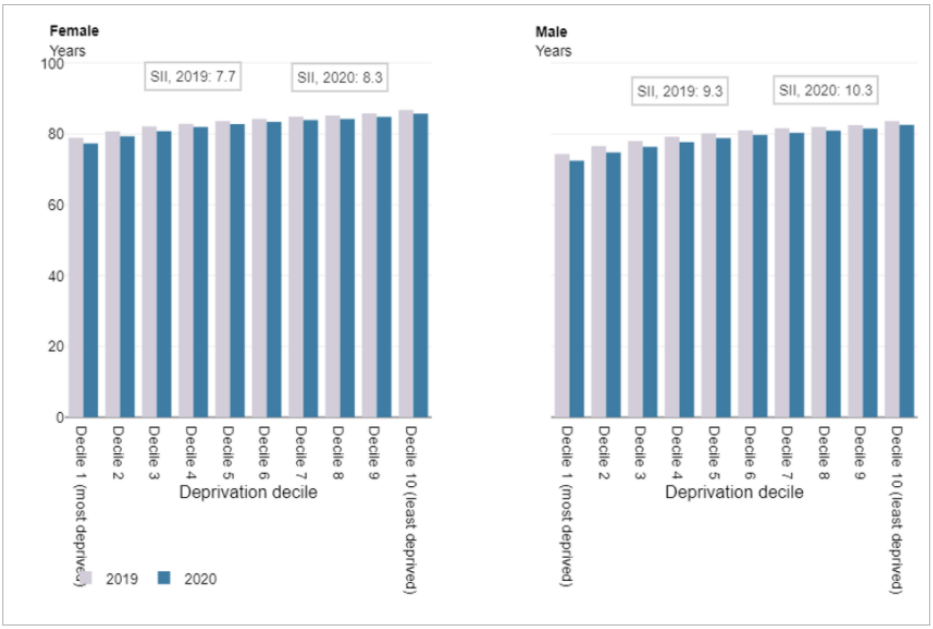
Figure 1 Provisional changes in Life Expectancy in England 2015 to 2020




Source: Data from PHE's Wider Impacts of COVID-19 on Health monitoring tool

The pandemic has worsened existing inequalities in life expectancy in areas of deprivation- the largest seen in two decades. The gap in life expectancy between the most and least deprived areas in England in 2020 was 10.3 years for males, one year larger than in 2019, and 8.3 years for females, 0.6 years larger than in 2019, as Figure 2 shows.

Figure 2 Life expectancy, by sex and deprivation decile, England 2019 and 2020




Source: [PHE Wider Impacts of COVID-19 on Health (WICH) tool]

## Predicted number of deaths

In real terms more people are projected to die every year –increasing the need for end of life and palliative care services. The following figures were ONS predictions for annual deaths in the UK and East Sussex from 2018 to 2043, Table 1. These figures were developed before the Covid-19 pandemic, which will affect their accuracy.[11]

**Table 1: Predicted Deaths in England and East Sussex until 2043**

| AREA | 2019 | 2025 | 2030 | 2040 | 2043 |
|---|---|---|---|---|---|
| **England** | 484,663 | 535,655 | 568,380 | 634,946 | 648,695 |
| **East Sussex** | 6,348 | 7,035 | 7,537 | 8,635 | 8,842 |
| **Eastbourne** | 1,252 | 1,366 | 1,448 | 1,655 | 1,693 |
| **Hastings** | 985 | 1,066 | 1,127 | 1,262 | 1,291 |
| **Lewes** | 1,075 | 1,199 | 1,284 | 1,457 | 1,496 |
| **Rother** | 1,319 | 1,462 | 1,590 | 1,868 | 1,915 |

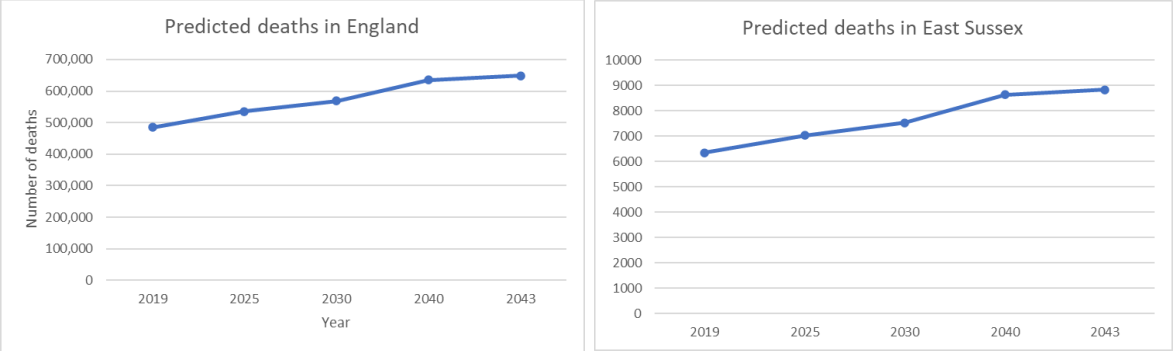
[11] Office for National Statistics [ONS] Population projections incorporating births, deaths and migration for regions and local authorities: Table 5 - Office for National Statistics

| | | | | | |
|---|---|---|---|---|---|
| **Wealden** | 1,716 | 1,941 | 2,089 | 2,395 | 2,448 |

Source: ONS National population projections: 2018-based[12]

The projected predicted number of deaths for England and East Sussex can be seen on Figure 3 below.

**Figure 3: Predicted Deaths in England and East Sussex until 2043**




Source: ONS National population projections: 2018-based[13]

# The impact of covid-19 on the uk

## Deaths in England and Wales

The impact of the Covid-19 Pandemic has been substantial. In the year 2020 there were 76,000 excess deaths in England & Wales (based on the 5-year average of previous years).[14]

Covid-19 was the leading underlying cause of death among men in 2020, replacing heart disease, and the second largest cause of death among women, after dementia and Alzheimer's disease. Dementia was also reported as the main pre-existing condition on 25.6% of deaths certificates involving Covid-19.[15]

As a consequence of the disruption to services and the backlog of care in all areas, the IPPR's *State of Health* forecasts that these disruptions will contribute to further deaths in future. For example 4,500 more cancer deaths are expected this year, and 12,000 more heart attacks and strokes over the next five years.[16]

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[12] Office for National Statistics [ONS] National population projections - Office for National Statistics

[13] Office for National Statistics [ONS] National population projections - Office for National Statistics

[14] Office for National Statistics [ONS] Deaths at home increased by a third in 2020, while deaths in hospitals fell except for COVID-19 - Office for National Statistics (ons.gov.uk)

[15] Public Health England. Health Profile for England 2021. https://fingertips.phe.org.uk/static-reports/health-profile-for-england/hpfe_report.html.

[16] Thomas C (2018) *The state of end of life care: Building back better after Covid-19*, IPPR. http://www.ippr.org/research/publications/the-state-of-end-of-life-care

Table 2 shows how many people died in England and Wales in the year 2020 compared to the previous 4 years.[17] There may have been under-reporting of Covid-19 deaths in 2020, especially at the start of the pandemic because people were less informed, and not everyone will have been tested.

**Table 2: Number of deaths in England & Wales 2016-2020**

| YEAR | NUMBER OF DEATHS | POPULATION (THOUSANDS) | CRUDE MORTALITY RATE (PER 100,000 POPULATION) | AGE-STANDARDISED MORTALITY RATE (PER 100,000 POPULATION) |
|---|---|---|---|---|
| **2020** | 608,002 | 59,829 | 1,016.20 | 1,043.50 |
| **2019** | 530,841 | 59,440 | 893.1 | 925 |
| **2018** | 541,589 | 59,116 | 916.1 | 965.4 |
| **2017** | 533,253 | 58,745 | 907.7 | 965.3 |
| **2016** | 525,048 | 58,381 | 899.3 | 966.9 |

Source: ONS Deaths in UK from 1990 to 2020[18]

## Recent trends in place of death[19]

Monitoring who dies and where is important in delivering high quality palliative and end of life care (PEoLC).

The Ambitions for Palliative and End of Life Care Framework highlights that having some personal choice in the place of care and death is fundamental to the experience of the person who is dying and for their families.

Understanding patterns of health and social care at the end of life found that most people would prefer not to die in hospital but at home, in a care home or in a hospice.

[17] Office for National Statistics [ONS] Deaths in the UK from 1990 to 2020 - Office for National Statistics (ons.gov.uk)

[18] Office for National Statistics [ONS] Deaths in the UK from 1990 to 2020 - Office for National Statistics (ons.gov.uk)

[19] PHE Palliative and end of life care factsheet: Recent trends in place of death NHS East Sussex CCG September 2021

For several years, the National Institute for Health and Care Excellence Quality Standard (QS13) for End of Life Care has used 'place of death' as a quality indicator for Palliative and End of Life Care. The Statistical Commentary: End of Life profiles demonstrates how place of death varies by cause of death, sex, age and geographical location.

The pandemic has had a profound impact on where people have died and the support they have received. According to the Office for National Statistics, deaths at home from all causes in 2020 were one-third higher than in the previous five years and deaths in care homes were 21% higher.

Although over half of deaths occurred in a private home during the pandemic Dying at home during the pandemic, reflects on whether this was due to preference or lack of choice. Many new ways of delivering EOLC have been introduced during the pandemic, especially in the community, as services have had to adapt. The community care sector had to increase their workload.[20]

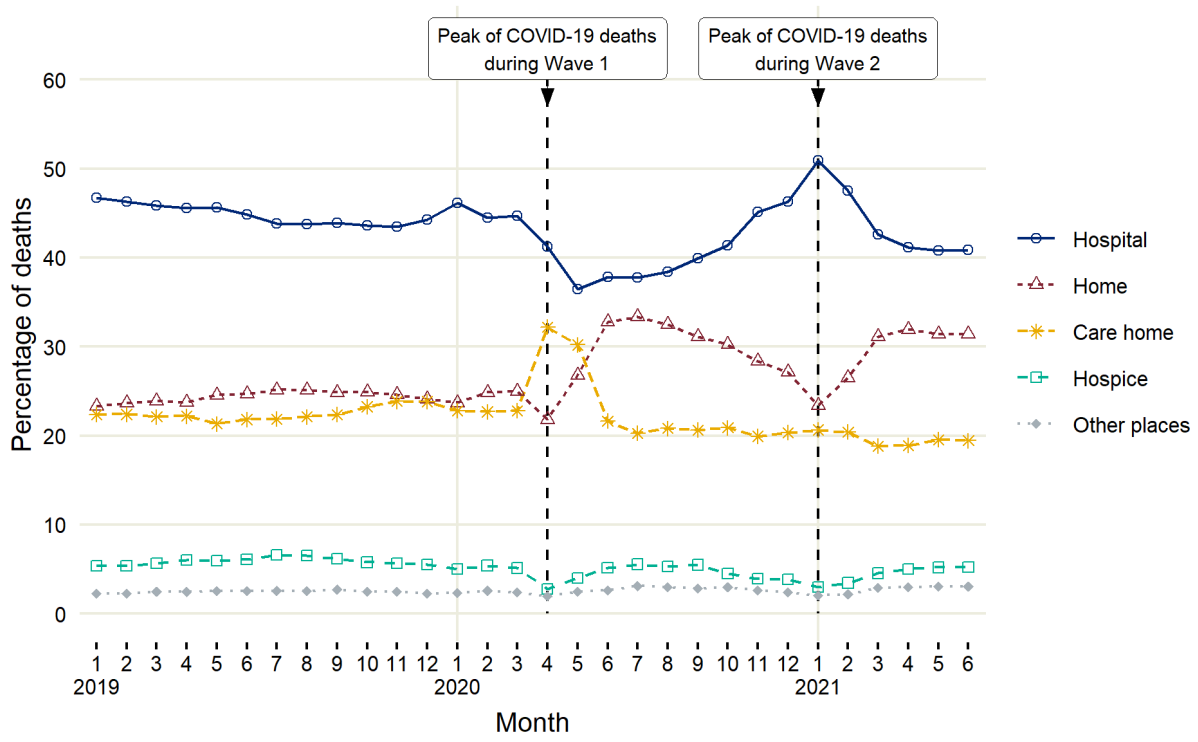
### Place of death in England 2019-2021

The monthly percentage of people who died in England, from January 2019 to June 2021 is shown by place of death (hospital, home, care home, hospice and other places) in Figure 4. Hospitals have the highest percentage of deaths (about 44%) followed by home (27%), care home (22%), hospice (5%) and other places (3%).

- the percentage of people dying in care homes showed a marked increase in April and May 2020, during the first wave of COVID-19
- the percentage of people dying in their home increased in April 2020 and has remained higher than previous years
- the percentage of people dying in hospital fell from January to May 2020, then started to rise again in September and peaked in January 2021

**Figure 4: Monthly trend (%) in deaths (all ages) by place of death: England (2019 to 2021)**

[20] Mitchell S et al 'Community end of life care during the Covid-19 pandemic: findings of a UK primary care survey' BJGP Open 13 July 2021; BJGPO.2021.0095. **DOI:** https://doi.org/10.3399/BJGPO.2021.0095

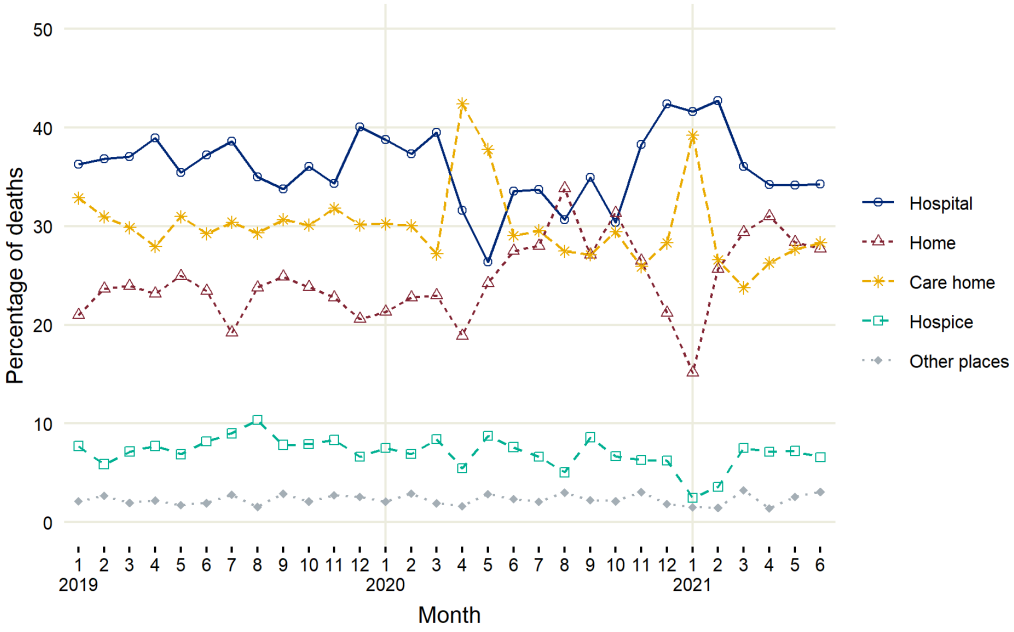



Source : PHE

**East Sussex CCG place of death 2019-2021**

The percentage of deaths by place of death for all ages is shown for this CCG in Figure 5. This percentage measure should be considered together with the total number of deaths which can be found in Figure 6.

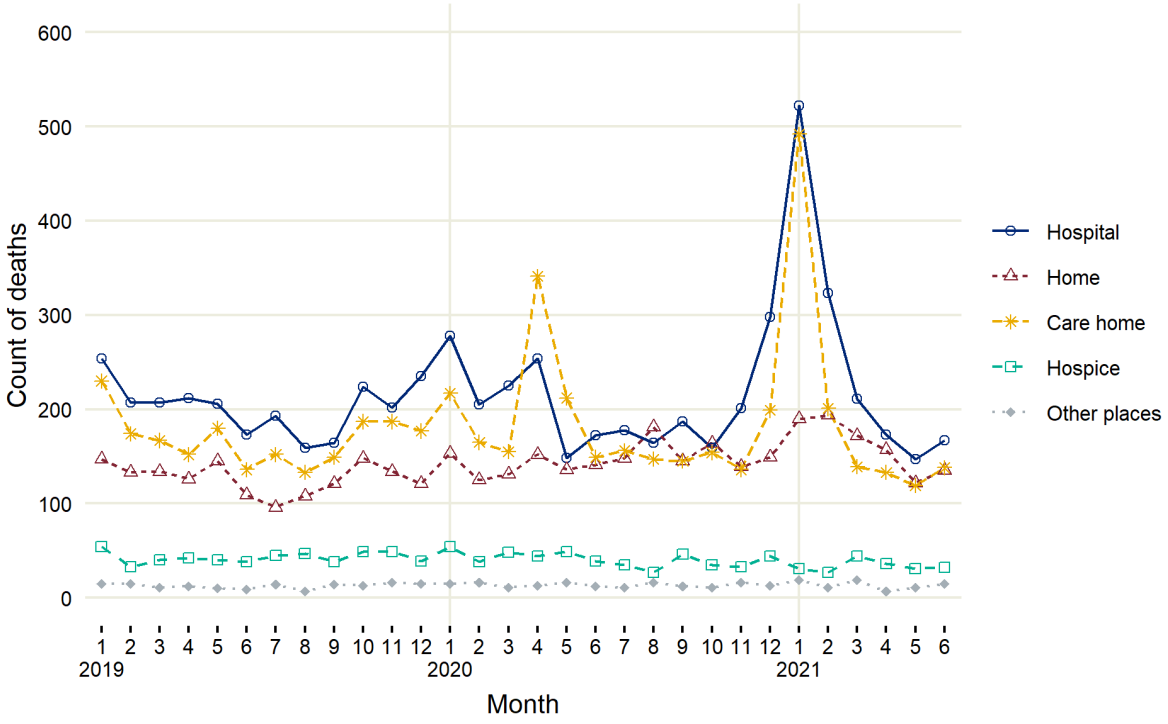
**Figure 5: Monthly trend (%) in deaths (all ages) by place of death: NHS East Sussex CCG (2019 to 2021)**




Source: PHE

Figure 6 shows the number of people who died by place of death (hospital, home, care home, hospice and other places). The monthly number of people who died for each of the five place of death settings, are presented for the years 2019 to 2021.

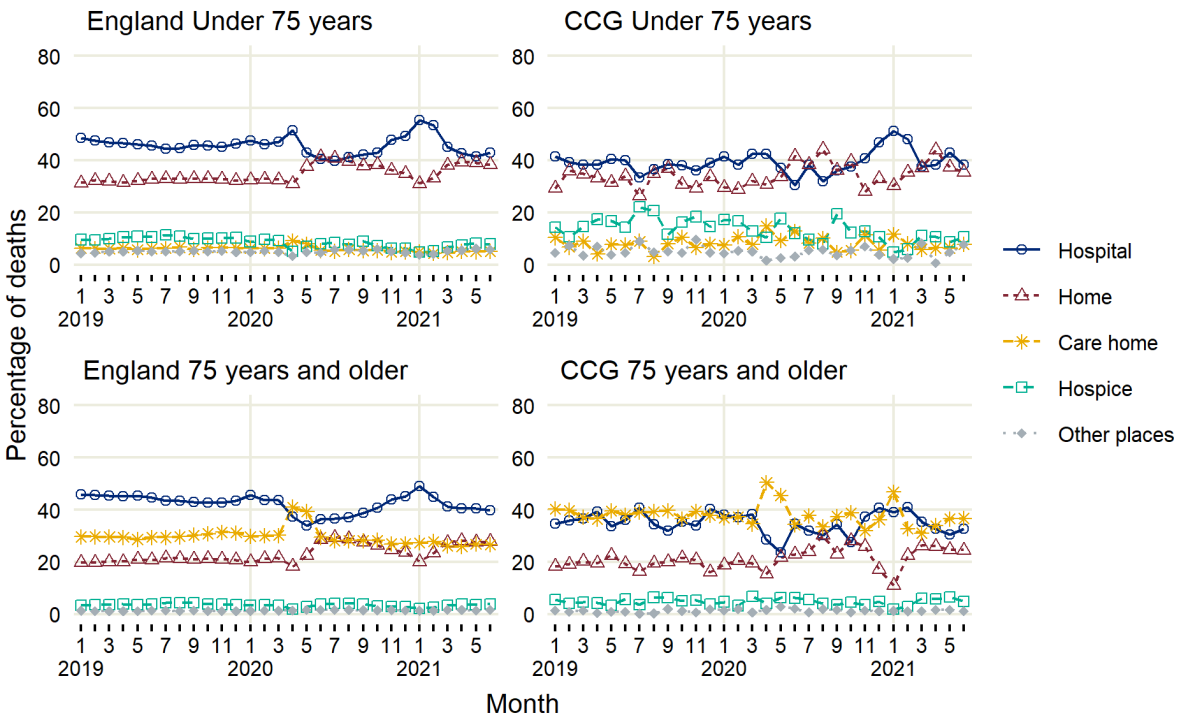
**Figure 6: Monthly number of deaths (all ages) by place of death: NHS East Sussex CCG (2019 to 2021)**




Source: PHE

Place of death can vary according to the age at which death occurs. Figure 7 shows the percentage of people dying in five settings (hospital, home, care home, hospice and other places), and is crudely split into two age bands (under 75 years, and 75 years and older). The data are shown for 2019 to 2021 and the monthly percentages are plotted on the trend line.

**Figure 7: Monthly trend (%) in deaths by place of death and age group (under 75 years, 75 years and older): NHS East Sussex CCG and England (2019 to 2021)**




Source: PHE

Table 3 below shows the annual number and percentage of people who have died by place of death (hospital, home, care home, hospice and other places) in 2019, 2020 and 2021. [The numbers for all ages are shown].[21]

The percentage of people who died in each of the place of death settings for these 2 years is compared with the percentage dying in that setting in 2019. The trend is shown as being either higher, lower or similar to the 2019 percentage.

**Table 3: Annual number and percentage of people who have died in East Sussex CCG by place of death in 2019, 2020 and 2021. All ages.**

2019

| Measure | Hospital | Home | Care home | Hospice | Other places |
|---|---|---|---|---|---|
| Number of deaths | 2,436 | 1,522 | 2,024 | 514 | 151 |
| Percentage of deaths | 36.6 | 22.9 | 30.4 | 7.7 | 2.3 |

**2020 (provisional)**

[21] The data are displayed in five sub-tables to enable comparisons in patterns of place of death by age at death: all ages; under 65 years; 65 to 74 years; ; 75 to 84 years; 85 years and older

| Measure | Hospital | Home | Care home | Hospice | Other places |
|---|---|---|---|---|---|
| Number of deaths | 2,469 | 1,764 | 2,176 | 492 | 162 |
| Percentage of deaths | 35.0 | 25.0 | 30.8 | 7.0 | 2.3 |
| Comparison with 2019 | Lower | Higher | Similar | Similar | Similar |

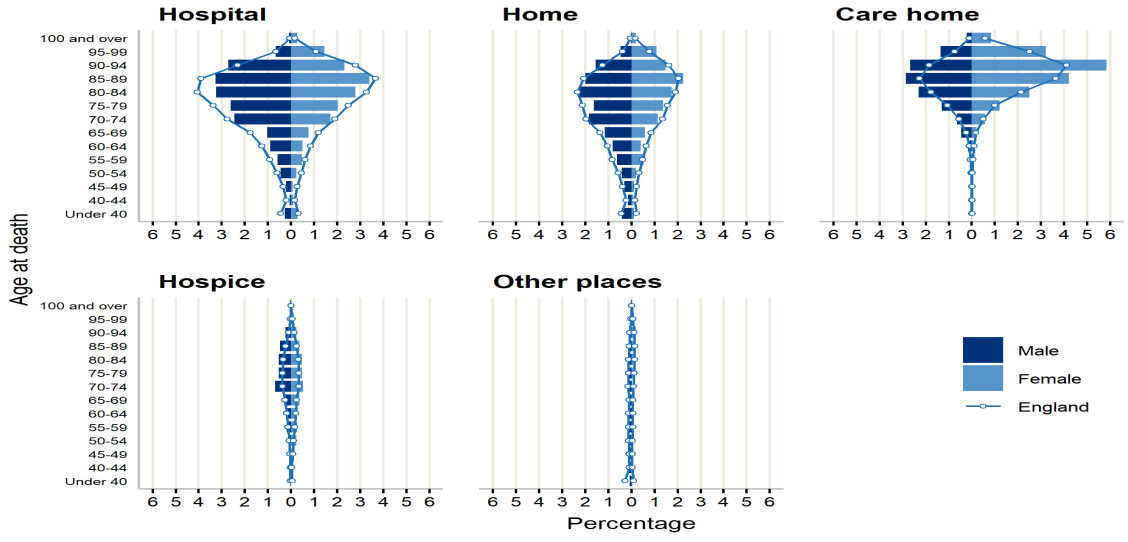
**2021 (provisional, incomplete)**

| Measure | Hospital | Home | Care home | Hospice | Other places |
|---|---|---|---|---|---|
| Number of deaths | 1,543 | 970 | 1,222 | 201 | 82 |
| Percentage of deaths | 38.4 | 24.1 | 30.4 | 5.0 | 2.0 |
| Comparison with 2019 | Similar | Similar | Similar | Lower | Similar |

Source: PHE

Figure 8 is a population pyramid comparing relative proportion of deaths in East Sussex CCG and England.

**Figure 8: Age and sex distribution of deaths by place of death: NHS East Sussex CCG and England (2020)**

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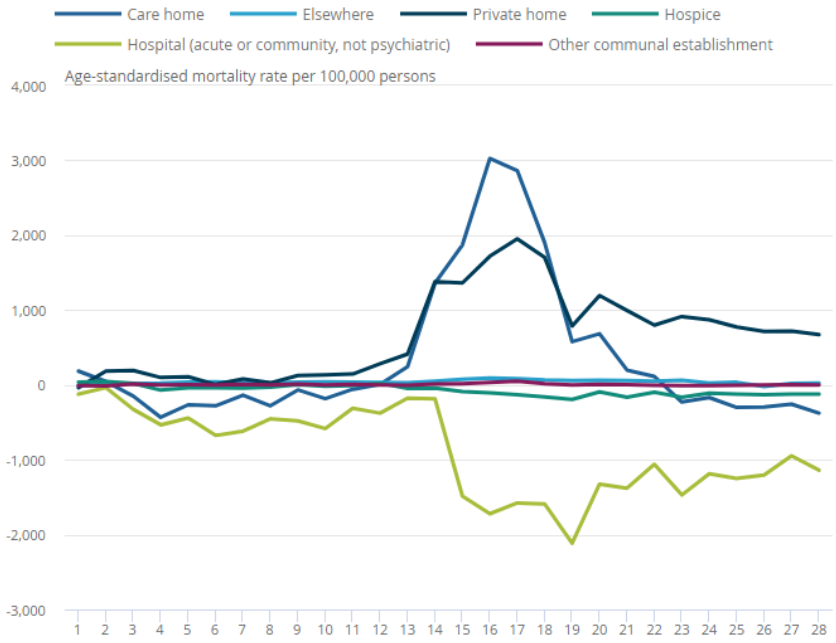
Source: PHE

People infected with coronavirus tended to die in hospital.[22] The contribution of COVID-19 to this increase in deaths in private homes was small. The tendency was for those people with existing life-limiting conditions to die at home, Figure 9.

**Figure 9. Non-COVID deaths occurring in different types of location weeks 1 to 28 in 2020 in England and Wales**




Source: ONS

**Place of death in the very elderly**

The number of people aged 85 years and over dying in hospital was slightly below the five-year average during 2020. However, among this age group, almost 31,000 more people than expected died in private homes and care homes.[23]

## Where would people prefer to die?

It is unknown whether these deaths at home were in accordance with people's previously expressed expectations. Even when there is a record of people's previously expressed wishes as part of advanced care plans, there can be practical difficulties with following these through. People's preferences might change as their circumstances change, or they might be too unwell to be moved between places.

Even though the pandemic has accelerated the trend for people to die away from hospital, it has always been the majority's preference to die away from hospital. The palliative care sector has advocated for this preference for a long time.  Coronavirus

[22] Analysis of death registrations not involving coronavirus (COVID-19), England and Wales - Office for National Statistics

[23] Office for National Statistics [ONS]

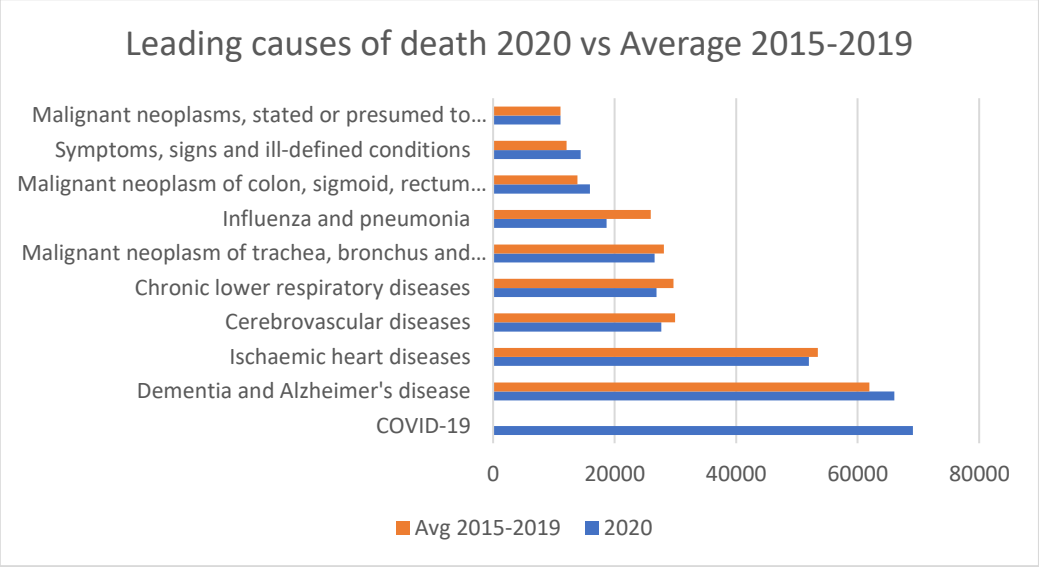
has illustrated the urgency with which we need to contemplate change and has brought the issue to the foreground.

In the VOICES survey 2015: 81% of people wanted to die at home and just 3% wanted to die in a hospital.[24] The family of the deceased was subsequently asked, after that person's death, whether they thought they died in the right place: 93% of family of those who died at home and 94% of family of those who died in a hospice thought this was the right place for them.

## Cause of death

As would be expected, the cause of people's death also changed in the pandemic. The leading cause of death in England & Wales 2020 was Covid-19, responsible for nearly 70,000 deaths. Despite the introduction of Covid-19 in 2020, the relative ranking of other causes of death was unchanged, Figure 10.

**Figure 10: Leading causes of death 2020 in England and Wales compared with 5 year average 2015-2019**




Source: ONS Monthly Mortality Analysis [25]

## Admission to hospital

Admission to hospital as an emergency is commonplace in the last 12 months of someone's life. On average, people in the UK are admitted to hospital three times in

[24] Office for National Statistics [ONS] National Survey of Bereaved People (VOICES) - Office for National Statistics (ons.gov.uk) Accessed 15/7/21

[25] Office for National Statistics [ONS] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/monthlymortalityanalysisenglandandwales/december2020#leading-causes-of-death

the last year of life, spending an average of 20 days in total as an inpatient.[26] Whilst an emergency admission might be necessary, it is also possible that these admissions reflect wider issues around the planning and delivery of end of life care.[27]

# The picture in east sussex

## Ageing and mortality in East Sussex

The concerns expressed earlier regarding an increasingly elderly population, with complex medical needs and frailty are very relevant to East Sussex.

East Sussex general practices have a higher percentage of registered patients who are over the age of 65 compared to the England average.[28] In 2020, 25.5% of the population for East Sussex were 65 or over, compared to 17.5% in England. In 2020, 12.2% of East Sussex population were 75 or over, compared to 8.1% in England.

The population across all age ranges, and especially the elderly population is projected to grow (see Table 4). The same trend can be seen across all districts and boroughs in East Sussex (Table 5). These projections were made before the coronavirus pandemic.

**Table 4: Projected elderly and very elderly populations across East Sussex**

| | 2019 | 2025 | 2030 |
|---|---|---|---|
| **EAST SUSSEX 65+** | 144,921 | 164,419 | 186,281 |
| **EAST SUSSEX 65-75** | 75,679 | 75,966 | 86,616 |
| **EAST SUSSEX 75-84** | 47,194 | 62,339 | 67,066 |
| **EAST SUSSEX 85+** | 22,047 | 26,113 | 32,599 |

Source: East Sussex in Figures[29]

**Table 5: Projected elderly populations Districts and Boroughs in East Sussex**

| | 2019 | 2025 | 2030 |
|---|---|---|---|
| **EASTBOURNE 65+** | 26,236 | 29,292 | 32,832 |
| **HASTINGS 65+** | 18,644 | 21,092 | 23,952 |

[26] Marie Curie 'Data briefing: emergency admissions – 2018' https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwiN-Lu78pTyAhUPV8AKHRGwBHoQFjAAegQIBRAD&url=https%3A%2F%2Fwww.mariecurie.org.uk%2Fglobalassets%2Fmedia%2Fdocuments%2Fmedia-centre%2F2018%2Femergency-admissions-report.pdf&usg=AOvVaw1ym6emEQr3Lviayk322QQw

[27] Knight T et al (2020) 'Advance care planning in patients referred to hospital for acute medical care: results of a national day of care survey' https://doi.org/10.1016/j.eclinm.2019.12.005

[28] PHE. Public Health England. Fingertips, National General Practice Profiles. https://fingertips.phe.org.uk/profile/general-practice. Published 2020

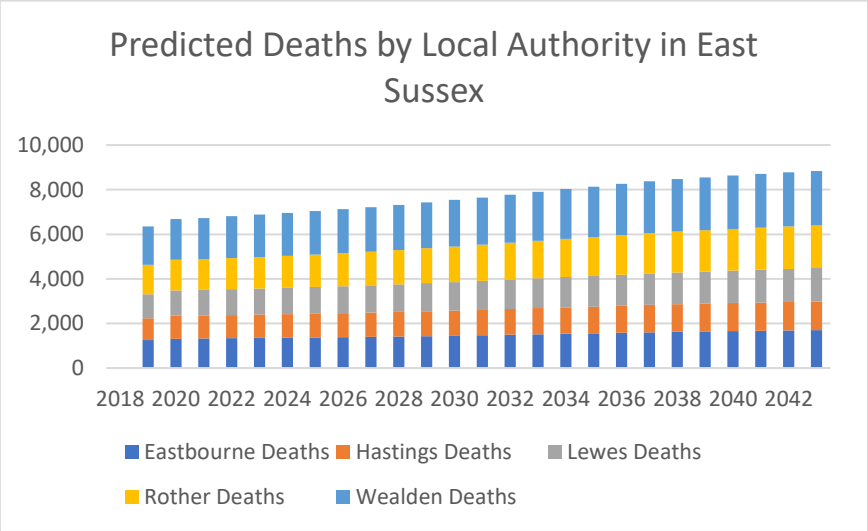
[29] East Sussex in Figures. Population projections. http://www.eastsussexinfigures.org.uk/webview/welcome.html. Published 2019.

| | | | |
|---|---|---|---|
| **LEWES 65+** | 26,625 | 29,845 | 33,272 |
| **ROTHER 65+** | 30,953 | 34,602 | 38,931 |
| **WEALDEN 65+** | 42,463 | 49,587 | 57,294 |

Source: East Sussex in Figures[30]

The number of people expected to die has been projected to increase each year, Figure 11 .

**Figure 11 Predicted deaths until 2043 by Districts and Boroughs in East Sussex**




Source: ONS Sub-national population projections: 2018-based[31]

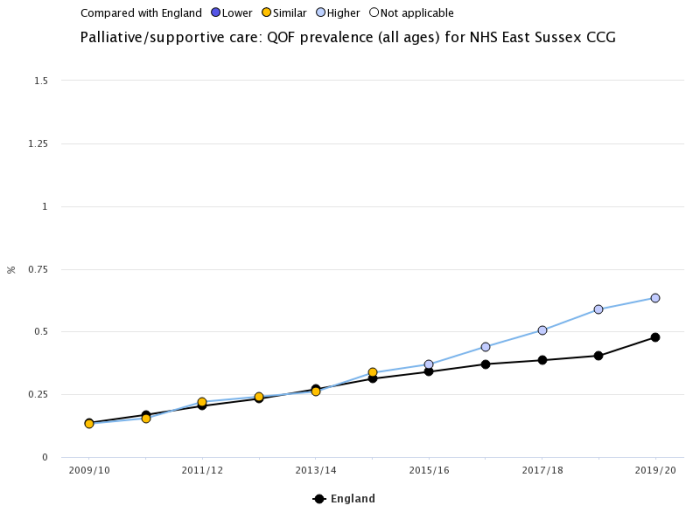
## Palliative care requirements in East Sussex

According to the general practice [QOF] annual figures, the prevalence of people requiring palliative care in East Sussex in 2019/2020 was 0.6% compared to England's average of 0.5%. East Sussex palliative care needs have been increasing and higher than the national average since 2015, Figure 12.

**Figure 12 QOF prevalence people receiving palliative care in general practice for East Sussex CCG compared with England 2009/10-2019/20**

[30] Ibid.

[31] Office for National Statistics [ONS] Subnational population projections for England - Office for National Statistics




Source: PHE Fingertips[32]

This snapshot might not accurately reflect all patients who might require palliative care. Some of the conditions for which palliative care referrals are advisable include: chronic kidney disease stage 4 and 5; end stage heart failure; and end-stage dementia. For example, in 2018 East Sussex CCG the prevalence of heart failure was 1.2%. The prevalence of chronic kidney disease in 2018 was 7.4%[33].[34]

# Changes since covid in East Sussex

## Deaths in East Sussex

Each local authority in Sussex follows similar trends to the UK for the number of deaths over time. Table 6 shows the number of deaths broken down by each Sussex 'place'.

**Table 6: Number of deaths by area 2017-2020**

| Area | 2017 | 2018 | 2019 | 2020 |
|---|---|---|---|---|
| England & Wales | 532,130 | 540,265 | 529,553 | 607,169 |
| East Sussex | 6,598 | 6,683 | 6,664 | 7,071 |
| West Sussex | 9,375 | 9,223 | 9,064 | 10,107 |

[32] PHE Fingertips National General Practice Profiles - Data - PHE Accessed 3/8/21

[33] (NB: only CKD stage 4 & 5 warrant palliative care referral,)

[34] PHE Fingertips Cardiovascular Disease - PHE Accessed 3/8/21

| | | | | |
|---|---|---|---|---|
| Brighton & Hove | 2,196 | 2,231 | 2,093 | 2,229 |

Source: ONS Death Registrations by Local Authority & Health Board[35]

To understand the overall picture of mortality it is important to note the change in the numbers of deaths as a result of COVID-19 and excess mortality. Excess mortality is defined as deaths beyond the expected number. The average from the previous 5 years is being used as the 'expected number'. It is not possible to identify which deaths would be expected and which ones contribute to excess mortality.

Table 7 shows the excess mortality experienced across Sussex in 2020 compared to the average from 2015-2019. (Note the difference in 2020 figures is due to Table 6 being death registrations that year and Table 7 based on year of occurrence, as well Table 7 being based on weekly data for 2020 – which works out as a very slightly different time period to the calendar year).

**Table 7: Excess mortality in 2020**

| Area | Average 2015-2019 | 2020 | Excess deaths |
|---|---|---|---|
| East Sussex | 6,650 | 7,310 | 660 |
| West Sussex | 9,274 | 10,158 | 884 |
| Brighton & Hove | 2,175 | 2,251 | 76 |
| Sussex total | 18,100 | 19,719 | 1,619 |

Source: ONS Weekly death data

The latest briefing from ONS suggests that although the pandemic has led to some mortality displacement (deaths in vulnerable people who would otherwise be expected to die in the following days, weeks or months), the displacement does not account for the amount of excess mortality seen since the start of the pandemic. They will be continuing to monitor mortality displacement as a result of COVID-19 in the coming months and years.[36]

We can see a further breakdown for each of the East Sussex districts in Table 8.

**Table 8: Number of Deaths by District 2017-2020**

[35] Office for National Statistics Death registrations and occurrences by local authority and health board - Office for National Statistics

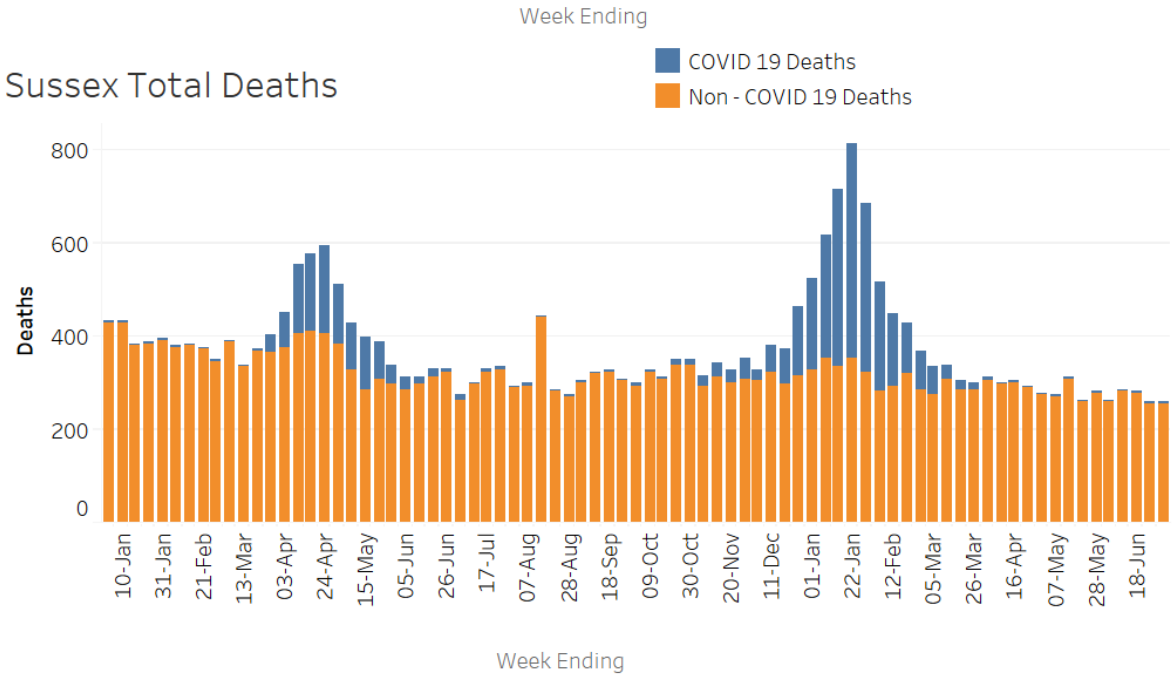
[36] Office for National Statistics Excess mortality and mortality displacement in England and Wales - Office for National Statistics (ons.gov.uk)

| | 2017 | 2018 | 2019 | 2020 |
|---|---|---|---|---|
| **EASTBOURNE** | 1,320 | 1,379 | 1,314 | 1,325 |
| **HASTINGS** | 990 | 1,013 | 996 | 1,057 |
| **LEWES** | 1,100 | 1,150 | 1,172 | 1,288 |
| **ROTHER** | 1,392 | 1,325 | 1,371 | 1,521 |
| **WEALDEN** | 1,796 | 1,816 | 1,811 | 1,880 |

Source: ONS Death Registrations by Local Authority & Health Board

Figures 13 and 14 put into perspective the Covid-19 deaths in Sussex during the pandemic from 2020 until June 2021. Whilst many people died in Sussex during the first wave in April 2020, there were a significant number of deaths in early 2021.

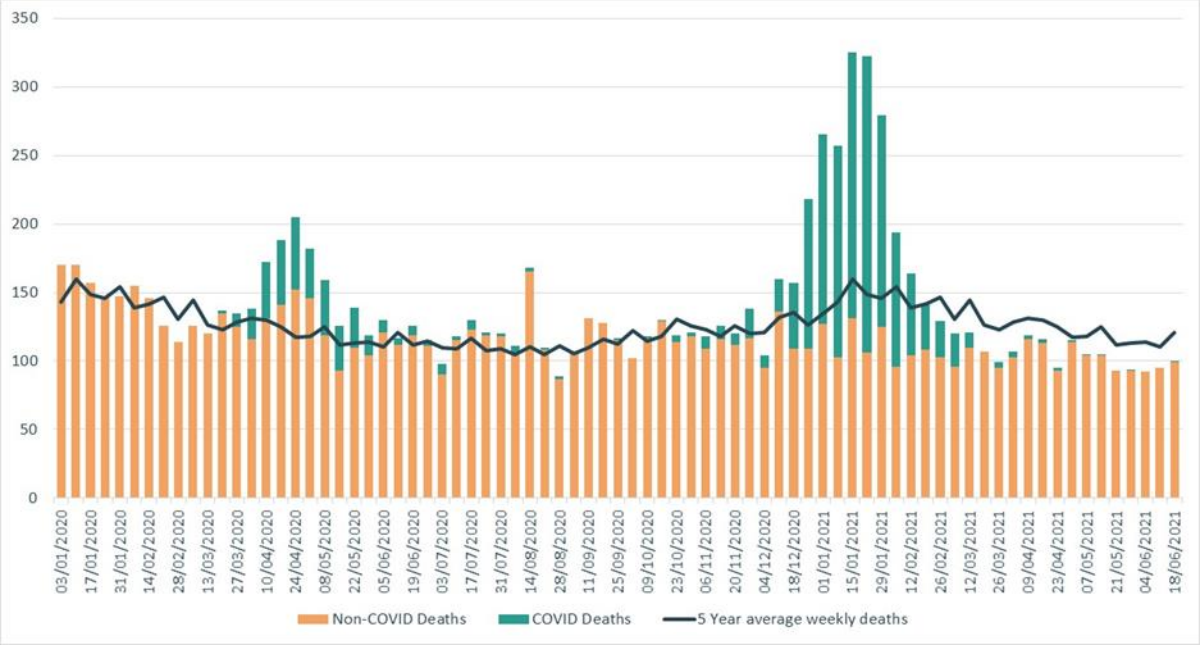
**Figure 13 Sussex weekly total deaths Jan 2020 to June 2021:**




Source Public Health Department East Sussex CC

From the beginning of 2020, there have been 1,962 deaths for East Sussex residents involving COVID-19, based on any mention of COVID-19 on the death certificate. 1,060 (54%) of these deaths occurred in a hospital setting and 755 (38%) occurred in a care home setting. Figure 14 shows waves one and two.

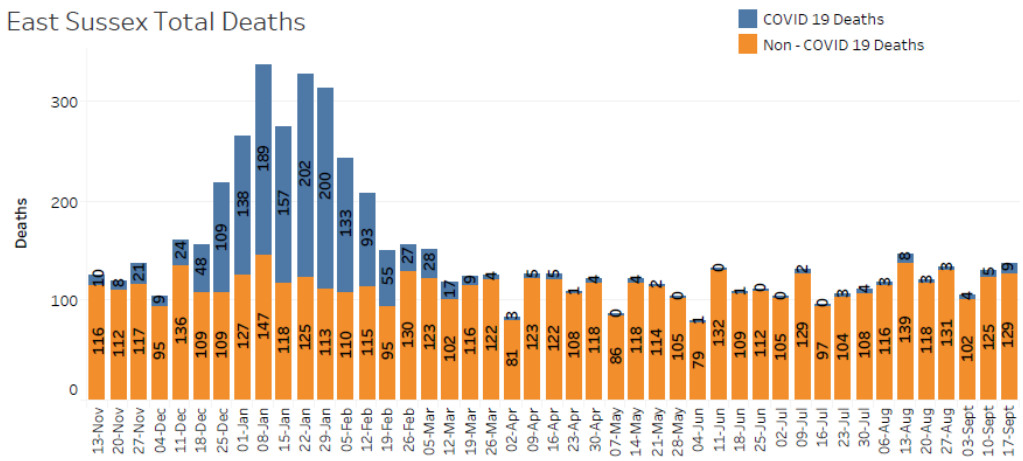
**Figure 14 Weekly total deaths for East Sussex residents Jan 2020 to June 2021**




Source: Public Health Department, East Sussex CC

Figure 15 shows East Sussex weekly total deaths from November 2020 to the present.

**Figure 15 East Sussex weekly total deaths 13th November 2020 to 17th September 2021.**



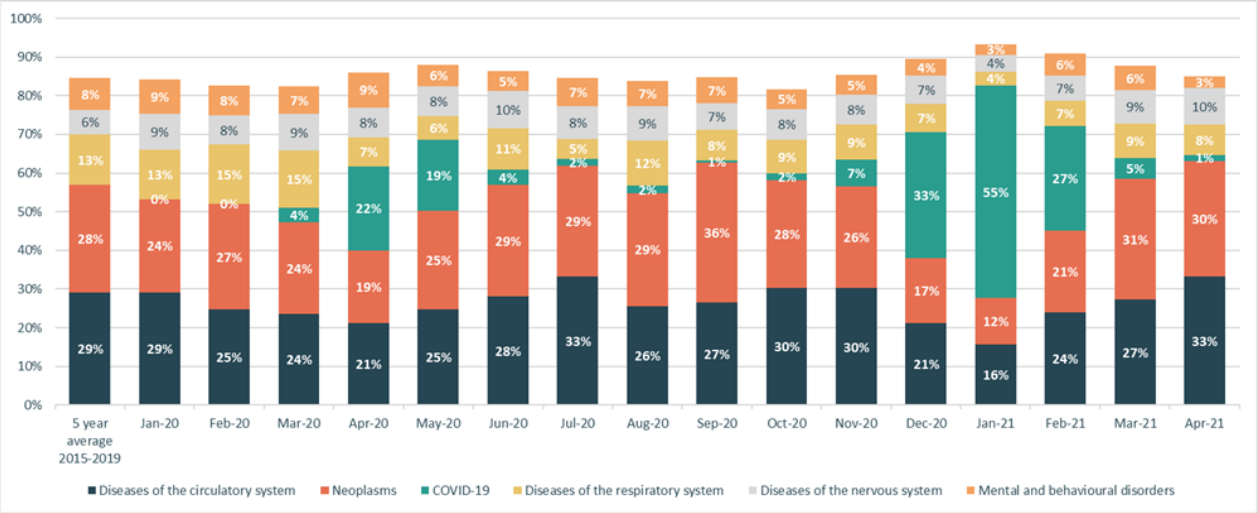

Source: Public Health Department, East Sussex CC

## Cause of Death in East Sussex

Typically, circulatory diseases and cancers made up at least half of deaths in East Sussex (57% of deaths 2015-2019), Figure 16.

Deaths from circulatory conditions (as a percentage of all deaths) were highest in July 2020 and April 2021, the months just following the peaks of wave 1 and wave 2. Deaths from cancers (as a percentage of all deaths) were highest in September 2020, Figure 16.

**Figure 16 Main causes of death by month in East Sussex Jan 2020 to April 2021 compared with previous five year average 2015-2019**




Source: Public health department, East Sussex CC

# End of life care in east sussex

## How end of life care is delivered in East Sussex

End of life care is currently delivered by the following organisations in East Sussex: acute and community hospitals, GP practices, out of hours GP services, care homes, hospices, social care, frailty services, and palliative care services.

There are 5 adult hospices available for East Sussex residents and these can be found on Hospice UK:[37]

- St. Wilfrid's Hospice, Eastbourne – 20 beds
- St Peter and St James Hospice and Continuing Care Centre, Chailey – 14 beds
- Hospice in the Weald, Pembury [Kent] – 15 beds
- The Martlets Hospice, Brighton and Hove – 18 beds
- St Michael's Hospice**,** St Leonards on Sea – 26 beds

In total there are 60 beds in hospices within the borders of East Sussex. As well as inpatient and respite services, the hospices offer: counselling and bereavement support; an outpatient clinic; occupational and creative therapy; physiotherapy; chaplaincy; and volunteer services.

[37] Hospice UK 'Find a Hospice' https://www.hospiceuk.org/about-hospice-care/find-a-hospice Accessed 3/8/21

# What are other areas doing?

Surrey Heartlands Health Care & Partnership have recently developed a Palliative and End of Life Care Strategy for 2021-2026.[38] The strategy matches the ambitions set out in NHS' 'Ambitions for Palliative and End of Life Care'. The delivery of the strategy will be monitored via both qualitative and quantitative measures.

A greater emphasis on advance care planning through further training on the use of the Recommended Summary Plan for Emergency Care and Treatment [RESPECT] process is planned. A public awareness campaign for 'Dying Matters Week' to encourage conversations with family about dying is also planned. Further training for the health and care workforce to enable skills and confidence around having honest conversations about death is planned. Access to bereavement services will be reviewed. Means of achieving the other ambitions are also given in detail.

# Conclusions

Behind the statistics of daily Covid-19 deaths, there were individuals who required end of life care at an extraordinary time. For each of those individuals, there will be even more people who have been bereaved, with their grieving processes inhibited by lockdowns, and visiting restrictions in hospitals and care homes. There will have been multiple healthcare professionals involved in their care, each of whom will have been doing their best with the resources they had during an extraordinary time.

When it comes to end of life care, we should be interested in more than just how many people die, what they died from, and where they die. The true measures of what helps someone die a 'good death' are: whether they suffered, whether their death was anticipated, whether they died where they wanted to die, with those they love near them, with their spiritual/psychological needs met. These are things we don't currently measure nationally, and admittedly might be difficult to measure.

There are plans within East Sussex palliative care teams to start to ask families the question: 'did your relative die a good death?' which is an effective way to ask all of the above.

There is important work on our current end of life care provision that is planned to be carried out in the local Sussex area,

Surrey & Heartlands Healthcare & Partnership End of Life Care Strategy is a good example which follows the goals set out in the NHS's 'Ambitions for Palliative and End of Life Care' and outlines realistic and measurable ways to achieve these.

[38] Surrey & Heartlands 'Palliative & End of Life Care Strategy 2021-2026' https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiNl8DO6ZTyAhVIZMAKHSBKDv4QFjAAegQIAxAD&url=https%3A%2F%2Fwww.surreyheartlands.uk%2Fwp-content%2Fuploads%2F2021%2F05%2F210511-Palliative-and-End-of-Life-Care-Strategy-summary-version-FINAL.pptx&usg=AOvVaw0OPEhpjh8urwj2VVWLaibG Accessed 3/8/21.

The most important message is that there needs to be more emphasis on the community side of the palliative care sector. During the year 2020 we saw a major shift towards dying at home. Even before the coronavirus pandemic, an increasing number of people were dying at home each year. In previous surveys, most people said they would rather die at home, and away from hospital. In order to do this properly, there needs to be adequate staffing in the community, with adequate training and access to resources.

The case for greater emphasis on community end of life care has been made elegantly in the Marie Curie 'Better end of life research report', Cicely Saunders manifesto, and IPPR's 'The state of end of life care: building back better after Covid-19'.[39]

Talking more about death and dying, and starting honest communication early, would be beneficial. The earlier on that it can be recognised that a person might be coming to the end of their life, the more opportunity there is to prepare for this and respect their wishes. This means more people can participate in advance care planning and might help avoid unnecessary hospital admissions that can accumulate into days/weeks away from home and family at the time when it matters most.

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Acknowledgements:

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[39] Thomas C (2018) *The state of end of life care: Building back better after Covid-19,* IPPR.

http://www.ippr.org/research/publications/the-state-of-end-of-life-care