

# End of life care

## Guide for councils

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# Introduction

Councils have a key role to play in helping people to die well and with dignity. This guide sets out how councils in England can play that role. The focus of this guide is adults during the final 12 months of their lives but the general principles also apply to children and young people. End of life care is loosely defined as the last year of life, but accurate predictions are difficult, which makes planning, preparation and embedding good practice important.

This guide was begun in early 2020 and was nearing completion in March 2020. It has been revised to reflect the new challenges posed by the COVID-19 pandemic. COVID-19 continues to be challenging for councils and their partners. The guide cannot cover all of the implications and issues that the pandemic has raised but seeks to help councils play a leading role in how people in their local areas experience end of life care, including during the pandemic.

There is as yet no comprehensive knowledge or analysis of the impact of COVID-19 on end of life care, but many issues and responses have been identified. This guide seeks to use this learning to help councils to support people at the end of their lives. By late September 2020 over 37,000 people in England had lost their lives from COVID-19.

The majority of these deaths occurred in hospitals<sup>1</sup>. It is important to note that the COVID-19 pandemic and the extraordinary demands it has placed on the health and care services have also had an impact on people who have not died from COVID-19, through social distancing, shielding and changed access to NHS and other services. The impact has been significant on families and unpaid carers too; changing their model of support limitations on hospital and care home visits and grieving processes. Like the end of life process itself, the impact of COVID-19 will vary widely and change over time.

Overall, we are living longer and remaining healthier for longer. Local government has been a major contributor to improving health and well-being. The major determinants of health; housing, jobs, education and so on, are all areas where councils and public health informed approaches can make a difference. Many councils already make a huge contribution to end of life care and have played a significant part in supporting people during end of life during the pandemic. The guide will include examples of best practice.

As well as the focus on improved quality of life and life expectancy, there has also been an increasing focus on providing the best care and support to people at the end of their lives. We all want a good life, but we also want a good death. Councils have a role here, in the provision of social care, commissioning services, providing information and advice and working in partnership with other agencies.

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1 <https://coronavirus.data.gov.uk/deaths>

This guide:

- sets out the policy context
- looks at what is meant by end of life care
- looks at the available data on end of life care
- sets out the statutory framework for councils role on end of life care
- examines the partnership and delivery structures on end of life care
- showcases some best good practice examples, which cover the key themes
- identifies COVID-19 issues and lessons learned for councils
- makes recommendations to councils to help them make a positive contribution to end of life care.

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

# Executive summary

Improving end of life care is important for everyone. Helping people to have choice and dignity at the end of their lives cannot be delivered by one agency. The NHS plays a key role, as do hospices and other charitable and voluntary groups. Councils also have an important role to play, both in the delivery and commissioning of key services such as home care and care homes, but also through their place-based leadership and through community inclusion.

This guide sets out the policy context for end of life care and key areas where councils deliver end of life care and where they can make a difference. These are based on the work of the multi-agency Ambitions Partnership and are:

- each person is seen as an individual
- each person gets fair access to care
- maximising comfort and wellbeing
- care is coordinated
- all staff are prepared to care
- each community is prepared to help.<sup>2</sup>

The data shows, on average, around 500,000 people die in England each year.

- 45 per cent die in hospitals
- 22.5 per cent of people died in care homes
- 23.8 per cent of people died in their own home.
- 5.9 per cent of people died in hospices.<sup>3</sup>

Many people express a wish to die in their own home, but data shows that only:

- 46.6 per cent of all deaths were in the usual place of residence
- 54.9 per cent of people over 85 years died in their usual place of residence.<sup>4</sup>

The guide sets out the Care Act responsibilities, which include social care assessment and care planning responsibilities, but also, the role of councils in ensuring there is a range of high-quality services available to meet needs.

The guide highlights how councils can work with key partners on end of life care through their local arrangements, such as their health and wellbeing boards or their health scrutiny role. Elected councillors will be interested in how and where people die in their local area and can engage their Public Health teams in exploring the data. For example, are people's wishes fulfilled regarding their place of death? And how end of life care and support is experienced by different communities in their area.

The guide also covers the early impact of the COVID-19 pandemic. It sets out changes to councils responsibilities and identifies some key areas to look at in relation to the pandemic.

Accompanying the guide are a number of online case studies, which showcase some of the approaches councils and their partners have taken to improving end of life care.

<sup>2</sup> <https://endoflifecareambitions.org.uk>

<sup>3</sup> Palliative and End of Life Care Profiles. PHE Fingertips 2018

<sup>4</sup> Palliative and End of Life Care Profiles. Death in usual place of residence. PHE Fingertips 2017.

**Improving end of life care is important for everyone and therefore important to councils. Working on end of life care is always an endeavour of partnership and collaboration. Councils can use this guide to help them to work with others to make a difference for local people. The good practice examples accompanying this guide online show that there are already excellent examples of work on end of life care and these are only a small number of the initiatives underway across the country. The COVID-19 pandemic emphasises the importance of these recommendations. It is important that people have the best end of life care during any situation.**

Councils could consider the following recommendations:

- Explore the quality of end of life care in your area through the health and wellbeing board, or similar body, on an annual basis. What is the end of life support offer like in your area? How the six aims of the Ambitions Partnership (page 5) are being delivered could be a place to start.
- Build on national data to create a set of data and metrics for your local area that helps to show how end of life care is delivered and experienced. Work with partners to improve the citizen feedback on end of life care. This intelligence can drive local improvement.
- Seek assurance that key responsibilities under the Care Act are being delivered and also that processes, such as those around NHS Continuing Health Care, are effective and person-centred.
- Consider whether there is a role for an elected member end of life care champion role to raise the profile of end of life care across the council and with partners.
- Explore the range of bereavement support services and how they have adapted under the COVID-19 pandemic.

# About end of life care

What do we mean by end of life care? The NHS definition is “End of life care is support for people who are in the last months or years of their life.”

The National Institute for Health and Care Excellence (NICE), identifies the last 12 months of someone’s life. NICE also produce a more clinically focused guide for care over the last 2 to 3 days of someone’s life.

People die in a range of settings: their own home, which might be a care home, in a care home setting which is not their permanent home, Hospices and Hospitals. Staff working in all these settings need to be competent and confident in delivering end of life care. A key aim of end of life care is to support people to die in the place of their choice whenever possible.

The exploration of this choice is often carried out in what is sometimes called a “difficult conversation”. It may be done by a medical professional, a family member, care staff or social workers. It is important that staff across the sector are able to have those conversations or support others who are having those conversations. Sometimes people may lack capacity through conditions such as dementia. Particular skills and sensitivity will be required. After a death family members and friends may find bereavement support helpful. Councils are often a key contact for this as they run burial and crematoria services.

Individuals and their families are key to developing the personalised approach to care more widely and particularly important in end of life care.

Councils have promoted and delivered personalised care for a number of years through self directed support and direct payments. The NHS Long Term Plan from 2019 sees the development of personalised care becoming business as usual and delivering universal personalised care by 2023/24.

## Policy context

End of life care has featured in legislation and policy over recent decades and has increasingly been part of wider policy and legislation. There is a balance between embedding a focus on good end of life care in all aspects of care and support and providing specific guidance. The focus has also been on live saving, changing technology and efficiency. However, the importance of end of life care has gradually increased.

The Care Act 2014 sets the legal framework for councils with social care responsibilities to support individuals nearing the end of their lives along with their families and carers.

The first national end of life care programme was established in 2004 and the first national strategy in 2008. Since then there has been increasing work on end of life care. Much of this work has been done by the NHS, although there have been major contributions from voluntary organisations too. One of the broad policy directions has been to give people more choice and autonomy about how they experience end of life support and where they die. Many people express a wish to die at home. Councils have contributed to this increasingly citizen focused approach.

## The national policy framework

Key elements of the national and local approach to end of life care include:

- the NHS sets out its approach to end of life care<sup>5</sup>
- there is a focus on settings at the end of life, preparedness, planning and well-being
- the NHS Long Term plan seeks to change the model of healthcare, which will change end of life care
- within Primary Care NHS there are voluntary Quality Outcome Framework (QOF) schemes to improve end of life care
- adult social care data is gathered in the Adult Social Care Outcomes Framework, (ASCOF). This is currently being revised and there is discussion of a new approach to end of life care
- the approach to end of life care is now part of the Strategic Plans produced by Integrated Care Systems and Strategic Transformation Plans.

The most comprehensive policy approach is set out by the Ambitions Partnership, the National Palliative and End of Life Care Partnership.<sup>6</sup> This is a multi-agency partnership including a range of statutory bodies, voluntary sector agencies, national charities and professional bodies. Local government is represented on the partnership by the Association of Directors of Adult Social Services (ADASS) and the Local Government Association (LGA).

The partnership identifies some key aims:

- palliative and end of life care must be at the heart of an integrated approach to care and support
- we want to work collectively to make the care that surrounds dying, death and bereavement as good as possible, for all.

They identify six ambitions for end of life care:

- each person is seen as an individual
- each person gets fair access to care
- maximising comfort and wellbeing
- care is coordinated
- all staff are prepared to care
- each community is prepared to help.

These ambitions are developed with detailed sets of building blocks needed to deliver the vision. There are eight foundations, which seen as necessary to deliver these ambitions:

- personalised care planning
- education and training
- shared records
- 24/7 access
- evidence and information
- involving, supporting and caring for those important to the dying person
- co-design
- leadership.

Councils have a contribution to each of these areas. The first of these foundations is something everyone should have:

“Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.”<sup>7</sup>

Several examples of new policy, analysis and guidance have come out during the pandemic relating to end of life care. The LGA and ADASS have produced a regular bulletin via the Adult Social Care Hub. The NHS has produced significant statistical information and guidance.

<sup>5</sup> [www.nhs.uk/conditions/end-of-life-care](http://www.nhs.uk/conditions/end-of-life-care)

<sup>6</sup> <http://endoflifecareambitions.org.uk>

<sup>7</sup> Ambitions for palliative and end of life care. A national framework for local action 2015-2020 NHSE.

Through their social care and public health services, councils with social care responsibilities will have engagement with this new policy, guidance and data. There are also impacts on councils without social care responsibilities, in terms of housing, waste disposal, support to other bodies and voluntary organisations and many other areas.

Much of this new policy and guidance had a focus on clinical practice, Personal Protective Equipment (PPE), social distancing and shielding. The impact of the practice and experience of end of life care is still emerging.

Whilst most COVID related deaths have occurred in hospital, there is increasing attention on the impact in care homes, for both people with and without COVID-19.

# Data

For councils and their partners to understand end of life care in their area and work together to improve it, gathering key data and information is essential. Understanding how people experience the end of life is crucial to improving it for everyone. The data collected helps us to understand this key question, inevitably the picture is incomplete.

Data is collected by the NHS and Public Health England (PHE). They currently produce palliative and end of life Care profiles.<sup>8</sup>

These resources show levels of variation in service provision and use, for example in the percentage of deaths in hospital or care settings by different age groups in different areas. This a rich source of data, which is a starting point for councils to enable them to understand how people experience end of life in their area.

Critically it shows the percentage of deaths with three or more emergency admissions in the last three months of life, which is an important indicator to understand the way end of life care works in each area.

The underlying causes of death can also be seen and data setting out some of the context, such as the number of care home beds and the rates of admission.<sup>9</sup>

The data here is regularly updated and new material added. There are also links to resources, intelligence and research.

There were around 500,000 deaths of all ages in England in 2018.

PHE currently collects detailed data on a wide range of aspects on death and end of life Care. There is continuing work to refine and improve this data.

Some key statistics:

- 45 per cent of all deaths occurred in hospital.
- 42 per cent of all deaths of people aged over 85 were in hospital.
- 22.5 per cent of all deaths occurred in care homes.
- 37.6 per cent of people dying over 85 years were in care homes.
- 23.8 per cent of all deaths were at home.
- 17 per cent of deaths of people over 85 years were at home.
- 5.9 per cent of people died in a hospice (although many Hospices provide support in the community as well).
- 2.3 per cent of people over 85 years died in a hospice.
- In 2018 7.5 per cent of deaths had three or more hospitals admissions in the last three months of life. This was an increase from 6.9 per cent in 2015.
- Many people express a wish to die at home and data is collected on numbers of people dying in their usual place of residence. This shows more people are dying in the usual place of residence. In 2017 -
  - 46.6 per cent of all deaths were in the usual place of residence
  - 54.9 per cent of people over 85 years died in their usual place of residence.

<sup>8</sup> <https://fingertips.phe.org.uk/profile/end-of-life>

<sup>9</sup> [www.gov.uk/government/collections/palliative-and-end-of-life-care#palliative-and-end-of-life-care-profiles](http://www.gov.uk/government/collections/palliative-and-end-of-life-care#palliative-and-end-of-life-care-profiles)

The data trends, prior to the COVID-19 pandemic, are broadly that fewer people die in Hospitals, slightly more are dying in care homes, more are dying at home and the numbers dying in Hospices is constant. A relatively small number of deaths take place in Hospices, so the mainstream NHS and care systems need to be able to provide good quality end of life care. Hospices already play a key role in supporting that wider system.

The data shows people who experience greater deprivation are more likely to die in hospital.

There is work underway to improve data and feedback on how individuals and their families experience end of life care. This is important as the data around end of life is largely quantitative; qualitative feedback on how people and their families experience things will help to enable improved care.

How different people and different communities experience end of life Care will be of interest to councils. In 2016 the Care Quality Commission (CQC) produced a report 'A Different Ending', which looked at inequalities in end of life Care.<sup>10</sup>

This report shares examples of how different approaches have been taken to tackling inequalities in access to end of life care. With public health an integral part of Local Government, this is a key role for councils.

Inevitably gathering data prompts questions of what it does and does not show. For example, the growing number of people dying in care homes, rather than hospital, is broadly positive, but councils may be keen to know how long people had lived in a care home before they died.

This data represents the known picture of deaths and end of life care prior to COVID-19. The impact of COVID-19 has changed this picture significantly since March 2020, with the existing patterns of dying now being very different. Three quarters of recorded COVID-19 deaths have been in Hospitals and many other COVID-19 deaths have been in Care Homes. There will inevitably have been an impact on deaths unrelated to COVID-19 too, but this is not yet clear. For example, data on deaths in preferred place of death and the numbers of people completing end of life care plans may show a different picture. Moreover, the processes of capturing and recording data will have been under great pressure at times during the pandemic.

COVID-19 prompts additional questions for local end of life care networks and councils:

- How well were people able to carry out existing end of life care plans during the pandemic?
- How were new end of life care plans created during the pandemic?
- Were people shielding who also might need support for end of life planning identified?
- How did Care Homes manage in delivering end of life care plans to residents with and without COVID-19?
- Given the greater impact of COVID-19 on people from black and minority ethnic communities is there local data on the impact of these communities?

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10 [www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EOLC\\_GoodPractice\\_FINAL\\_2.pdf](http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_GoodPractice_FINAL_2.pdf)

# The role of councils

The statutory duties of Councils are set out in the 2014 Care Act. This also enshrines the personalised approach. Councils have the following responsibilities towards individuals and their families under the Act.

“10.1 Care and support should put people in control of their care, with the support that they need to enhance their wellbeing and improve their connections to family, friends and community.

10.2 The person must be genuinely involved and influential throughout the planning process and should be given every opportunity to take joint ownership of the development of the plan with the council if they wish, and the council agrees.”

These are core parts of a good approach to end of life care

Councils have responsibilities to undertake needs assessments:

6.13 Councils must undertake an assessment for any adult with an appearance of need for care and support, regardless of whether the council thinks the individual has eligible needs or of their financial situation.

Eligibility for support is set out as follows:

6.103 In considering whether an adult with care and support needs has eligible needs, councils must consider whether:

- the adult’s needs arise from or are related to a physical or mental impairment or illness
- as a result of the adult’s needs the adult is unable to achieve 2 or more of the specified outcomes (which are described in the guidance below)
- as a consequence of being unable to

achieve these outcomes there is, or there is likely to be, a significant impact on the adult’s wellbeing.

An adult’s needs are only eligible where they meet all 3 of these conditions.

There are ten outcomes set out in the Act:

- managing and maintaining nutrition
- maintaining personal hygiene
- managing toilet needs
- being appropriately clothed
- being able to make use of the adult’s home safely
- maintaining a habitable home environment
- developing and maintaining family or other personal relationships
- accessing and engaging in work, training, education or volunteering
- making use of necessary facilities or services in the local community, including public transport, and recreational facilities or services
- carrying out any caring responsibilities the adult has for a child.

There is no specific guidance in the Care Act relating to end of life care, although the principles underpinning good end of life care run through the Act.

Personal budgets are an area where the council can help to support the delivery of support to individuals at the end of their lives.

Councils and their partners in the provision of housing and adaptations may also have responsibilities to people at the end of their lives.

A person's wish to die at home may need involvement from another council with housing responsibilities, or a Housing Association.

The legislation also places a duty on councils in relation to market development. Section 5 of the Care Act sets out duties on councils to facilitate a diverse, sustainable high-quality market for their whole local population, including those who pay for their own care and to promote efficient and effective operation of the adult care and support market as a whole.

Many people die at home or in care homes, care in both settings is substantially commissioned by councils. The duty in the Care Act extends to services, which the Local Authority does not directly commission, therefore it is important for councils to be assured that their commissioned and market engagement are, for example, helping to deliver the six key aims of the Ambitions Partnership. Particularly important is whether care staff and managers are trained in end of life care and connected to local networks.

Councils can play an important role in ensuring that the workforce is available to deliver high quality end of life care.

The Care Act also places responsibilities on local government to provide information and advice to enable people to "make good decisions about care". Councils are unlikely to be the only source of information and advice, but they do have a role in making sure that it is appropriate and tailored to local needs and that it is easy to access.

Councils also have wide well-being powers. Such as helping to support and improve end of life care is a key aim to further the well-being of local people.

Councils also have a role in supporting people after the death of a loved one. Bereavement services are often commissioned or funded by councils.

Often people are signposted to these services by local authority crematoria, burial and registrar services. During the pandemic there have been restrictions on attendance at funeral and cremations in addition to sometimes reduced access for relatives and friends to people who are at the end of their lives. Bereavement services have had to adapt during the pandemic. The National Bereavement Association have run regular sessions on the web to share best practice and support bereavement support services.

Recognising the impact of the pandemic, on 31 March 2020 the Department of Health and Social Care (DHSC) introduced a set of temporary easements to the Care Act recognising that the impact of COVID-19 required a differentiated response from councils.<sup>11</sup>

In March 2020 the DHSC introduced new hospital discharge requirements in relation to COVID-19. This was followed by the DHSC Adult Social Care Action Plan/COVID-19. This gave a wide range of guidance to Social Care in relation to COVID-19, and included four paragraphs on end of life care:

"Supporting people at the end of their lives

3.10 Sadly, many older people living in care homes die not long after their arrival. Approximately 10,000 people die each month in care homes. While many live for longer, some estimates suggest that about a third die within 6 months of entry to a care home and almost a half within the year (45 per cent).

3.11 People in care homes and their families should be involved, as much as possible, in planning and decisions about their health and care, including end of life care, and should be supported in having honest, informed and timely conversations. While we have recommended that care homes limit unnecessary visits, we are clear that visits at the end of life are important both for the individual and their loved ones and should continue. Our guidance has set out steps care homes should take to ensure

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<sup>11</sup> The full guidance can be found at: [www.gov.uk/government/publications/coronavirus-COVID-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities](https://www.gov.uk/government/publications/coronavirus-COVID-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities)

appropriate infection control during these visits. We will continue to work with the sector to develop and share best practice on how to enable visits at the end of life in a safe and compassionate way.

3.12 It is unacceptable for advance care plans, including 'Do Not Attempt Resuscitation' orders, to be applied in a blanket fashion to any group of people, and CQC have been urgently contacting providers where this practice has been brought to their attention. Everyone at risk of losing mental capacity or nearing the end of their life should be offered the opportunity and supported, if they wish, to develop advance care planning that make their wishes clear, and to make arrangements, such as lasting power of attorney for health and social care decisions, to put their affairs in order. This must always be a personalised process.

3.13 End of life care, including palliative care, must continue to be planned in a holistic way involving social care, community nursing, general practice, occupational therapy, and others. This includes access in people's homes and care homes to professionals and equipment that support this. We will monitor and take action to support collaboration across health and social care settings where needed to support appropriate access, working with CQC and others to access local intelligence."

The Coronavirus Act of March 2020 among other things changed the guidance on NHS Continuing Health Care. There is further detail on this in the section below and in the case study examples.

## Continuing Health Care

Councils also have responsibilities in relation to who is specifically responsible for the funding and delivery of some end of life care. These include ensuring people are referred for Continuing Health Care (CHC) and being part of the multi-disciplinary team that undertakes the assessment.

Some people receiving care and support are eligible for fully funded CHC. There is a National Framework for Continuing Health Care<sup>12</sup>, which sets out the assessment process and eligibility criteria for CHC funding. Those people who are assessed as having a "primary health care need" are funded by the NHS and are not required to contribute to the cost of their care package. Those in receipt of CHC are regularly reviewed and if eligibility changes funding responsibility may shift to the individual or the council. There is a statutory appeals process for individuals, families or their advocates to appeal a CHC decision.

There is a CHC 'Fast Track Assessment' to ensure that those individuals approaching the end of their life can access rapid care and support without having to undergo a lengthy assessment process.

The NHS sets the process out as follows:

"If your health is deteriorating quickly and you're nearing the end of your life, you should be considered for the NHS Continuing Healthcare fast-track pathway, so that an appropriate care and support package can be put in place as soon as possible – usually within 48 hours."

The NHS is moving forward with an agenda for universal personalisation over the next few years, which will increasingly see people with NHS CHC needs offered Personal Health budgets. Councils have experience of implementing more personalised approaches through adult social care and can play a role in helping to ensure mechanisms improve the choice and levels of control available to people.

The aim of the fast track process is to make quicker decisions for people at the end of life and reduce stress for them and their families. This person-centred approach is in line with wider approaches to end of life care. Councils should be assured that these processes work well and people at the end of their lives receive quick and uncomplicated support.

<sup>12</sup> [www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare](http://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare)

The Coronavirus Act of 27 March 2020 changes the guidance regarding NHS CHC. These remain in place in August 2020<sup>13</sup> This made two changes and included a crucial element about the source of funding for care. The two changes are that:

Section 14 of the Act states that a relevant body or NHS Trust does not have to comply with their duties to:

- a) assess an individual for eligibility; or
- b) have regard to the National Framework in relation to assessing individuals for eligibility.

The critical third element is that the Government have agreed that the NHS will fund all new, or extended, out of hospital health and social care packages to enable faster discharge and free up numerous hospital beds which may be required for other acute patients. Further guidance on how health and care systems should support the safe and timely discharge of people who no longer need to stay in hospital can be found on Gov.UK.<sup>14</sup>

However, it is important to note that CHC legislation and policy may change in the future.

## Partnership and delivery structures

There is a National End of Life Care programme board, which is led by the NHS and has representation from ADASS and the LGA. The board is connected closely with the Ambitions Partnership but has more of a focus on how statutory bodies deliver end of life care.

There are now 44 Sustainability and Transformation Partnerships, or Integrated Care systems across England<sup>15</sup>. They are strategic delivery bodies, which include NHS organisations and councils.

Each has a strategic plan, which will contain a section on end of life care. These structures embed the approach of improving end of life care as part of the overall improvement and transformation of the health and care system.

At a more local level there is more variety, with groups working on end of life care in most areas. These may be joint groups, which are sub-groups of health and wellbeing boards, or they may be groups led by a Clinical Commissioning Group or a Hospital Trust. Very often a local hospice and other local voluntary groups will play a key role. There is no prescribed or preferred model, but councils should be involved and have confidence that the arrangements are effective. A measure might be whether such groups have the capacity and influence to have an impact on the six aims and eight foundations of the Ambitions Partnership.

Councils do have statutory mechanisms to explore and influence end of life care. This could be done through the Health and Wellbeing Board, or through a council's statutory health scrutiny powers. Councils have a wide variety of joint partnership with the NHS and other partners, which may also be places to discuss and work together to improve end of life care.

What is clear is that working in partnership to embed the principles of good end of life care is essential.

## COVID-19 Issues for councils relating to end of life care

Whilst the overall well-being of the health and care system is vital for end of life care there are important areas, which concern councils. Councils have an overall well-being responsibility and should be concerned to assure themselves that under COVID-19 there are strong partnership arrangements looking at end of life issues, such as identification, care planning, care delivery and differentiation between different communities.

<sup>13</sup> [www.legislation.gov.uk/ukpga/2020/7/section/14/enacted](http://www.legislation.gov.uk/ukpga/2020/7/section/14/enacted)

<sup>14</sup> [www.gov.uk/government/collections/hospital-discharge-service-guidance](http://www.gov.uk/government/collections/hospital-discharge-service-guidance)

<sup>15</sup> [www.england.nhs.uk/integratedcare/stps](http://www.england.nhs.uk/integratedcare/stps)

Councils have their Care Act responsibilities in terms of assessing and meeting need, which inevitably are challenged by the pandemic. Critically they have market oversight responsibilities also, which require them to ensure high quality services are available. There are enormous pressures on the care home sector, ranging from personal protective equipment (PPE) provision, staffing, financial viability, admissions policies, handling deaths in care, contacts with relatives and friends and many other issues. Councils should play a key role in understanding, highlighting and mitigating these issues.

As before COVID-19 end of life care is not simply an NHS and social care issue. There are important roles for third sector organisations and for other council services, such as housing and cemetery and crematoria services.

The case studies included in and accompanying this guide give examples of good practice in end of life care before and during COVID-19 and provide examples of councils and their partners are working together to improve end of life care.

Since the advent of the pandemic more guidance and resources have become available:

**Hospice UK produces a valuable digest of information and resources**

[www.hospiceuk.org/docs/default-source/echo/COVID-19-echo/the-conversation\\_resources\\_collection\\_10june2020.pdf?sfvrsn=2](http://www.hospiceuk.org/docs/default-source/echo/COVID-19-echo/the-conversation_resources_collection_10june2020.pdf?sfvrsn=2)

**The British Geriatrics Society, BGS also produces a useful body of material:**

[www.bgs.org.uk/resources/COVID-19-end-of-life-care-in-older-people](http://www.bgs.org.uk/resources/COVID-19-end-of-life-care-in-older-people)

**There is guidance from the Care Quality Commission, CQC:**

[www.cqc.org.uk/guidance-providers/adult-social-care/information-adult-social-care-services-during-coronavirus-outbreak](http://www.cqc.org.uk/guidance-providers/adult-social-care/information-adult-social-care-services-during-coronavirus-outbreak)

# Case examples

Many councils already make a significant contribution to end of life care in their area. A range of examples of how councils and their partners have taken innovative and positive approaches to end of life care will be published online at the LGA website to support this guide. Two examples are included below.

## Kent County Council

Kent County Council produced a major guide to the development of end of life care in the county. It was first produced in 2017 with major input from a wide range of partners and revised in November 2019.

The guide sets out what has been achieved across the county since the first iteration of the guide in 2017. It sets out from a council perspective the wide-ranging partnership work involved in end of life care. It relates this work to the Ambitions Partnership goals. There is also a large section of supporting documents and resources.

The guide makes clear the council's commitment to and role in end of life care.

[www.kent.gov.uk/\\_\\_data/assets/pdf\\_file/0020/71408/End-of-Life-guidance-document.pdf](http://www.kent.gov.uk/__data/assets/pdf_file/0020/71408/End-of-Life-guidance-document.pdf)

## Royal Borough of Greenwich

### Partnership working across the borough

There is strong partnership working in The Royal Borough of Greenwich (RBG) to develop and improve the local offer. The overall objective is that people at the end of their lives and their families can be well supported and their outcomes improved through care and support that is integrated around the individual.

A strategy group meets regularly with active participation and input from partner organisations across our local system. Their objective has been to map the person's journey across the network of local services (from early identification, care planning, specialist clinical provision to bereavement support after someone has died). The strategy group also identifies inconsistency or variation as well as examples of good practice.

The ambitions in 2018/19 and this current year have been very focused on understanding the existing provider landscape, early identification of end of life patients and connectivity between providers.

Partners on the Greenwich Strategy Group have identified areas where services could be improved, and the following projects of work have been implemented or are in development:

- Improved capacity for RBG's Occupational Therapy team to support known clients with palliative needs in the community. The aim of the project is to help reduce pressures on family carers and other domiciliary services and reduce the likelihood of emergency attendances at Accident and Emergency.

- End of life care education programme for care homes – being developed in line with enhanced health in care homes framework.
- A partnership initiative being piloted with St Christopher's Hospice to provide bespoke domiciliary care to people in the last year of life, where the support workers have all worked in a hospice environment and have undertaken additional training to ensure good understanding of the support required for end of life.
- Education and training for GPs to help them identify people approaching end of life in a timelier fashion so that they can access better support, earlier. This includes training around communication, symptom management and understanding of care pathways.
- The RBG had a report at its Health and Wellbeing Board in January 2020, which outlined work undertaken by the council and partners on end of life care. It outlines the services available in Greenwich delivered by a range of organisations, improvements being made, and the steps being taken to strengthen collaboration across all relevant partners so that services are as coordinated as possible.

Finally, an infographic was produced as an appendix to a Health and Wellbeing Board report on end of life care in the borough. The slide gives key data so that the council and its partners can understand how people die in the borough.



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