

# NICE impact end of life care for adults



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## Impact of the coronavirus (COVID-19) pandemic

This report looks at the impact of our guidance using data collected before the COVID-19 pandemic.

In response to COVID-19, care has been delivered differently. As a result some people, and those important to them, may have had a less positive experience.

We do not yet know the full impact the pandemic has had on end of life care. It is likely that changes made during this time will influence how care is delivered in the future.

## Insight from Marie Curie



Julie Pearce (Chief Nurse and Executive Director of Caring Services) and Dr Sarah Holmes (Medical Director, Service Transformation & Innovation).

Together they consider NICE's role in improving end of life care.

Many people are unable to access support at the end of life. The quality of care can be variable depending on location, social and cultural background, and diagnosis.

The COVID-19 pandemic has shone a light on many gaps in service provision and organisation. Now, there is a need for more evidence to help drive improvements in accepting a prognosis, preparing for death, loss and bereavement, and closing gaps in quality of care across all settings. We need to understand and strengthen the impact of NICE guidance on people's experience of end of life care.

# Why focus on end of life care for adults?

Around [half a million people die in England each year](#). With an ageing population, the [annual number of deaths](#) is projected to increase. In addition, the COVID-19 pandemic has led to an [increase in the excess death rate](#).

The [One chance to get it right](#) report from the Leadership Alliance for the Care of Dying People states that people are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent as well as those with conditions that mean they are expected to die within 12 months.

End of life care enables supportive and palliative care needs to be identified and met throughout the last phase of life and into bereavement. Palliative and end of life care is provided by disease-specific teams, generalists in the community and hospitals, and specialists in palliative care in all settings. This care ensures that people live well until they die.

Effective end of life care improves the quality of life of the dying person and those important to them. It is achieved by early identification, assessment and treatment of pain and other distressing symptoms, while integrating the psychological, social and spiritual aspects of the person's care.

There is a lack of published data about end of life care services for the last 12 months of life, so the main focus of this report is on care in the last 2 to 3 days of life in acute settings.

## We have published

4

Guidelines

2

Quality  
standards

1

Technology  
appraisal

1

COVID-19  
rapid guideline

# Care of people approaching the end of life

The [NICE guideline on end of life care for adults: service delivery](#) and [quality standard on end of life care for adults](#) say that people approaching the end of life should be identified in a timely way. Effective and timely identification can allow people, and those important to them, to make decisions about their care. This can help health and social care providers ensure that peoples' priorities are recognised and, where possible, met.



**Only 60% of people in their last 3 months of life knew that they were likely to die**

([National Survey of Bereaved People \[VOICES\]](#), 2016)

Either health or social care practitioners in any setting can start identification. They should talk to the person, and their family and carers, about the benefits of being identified and this being recorded on a register or similar system. This conversation should be carried out sensitively and take into account that not all people want to be identified as approaching the end of their life.

**'I ask myself whether I would be surprised if they were not alive in 12 months. This depends on their degree of frailty and dependency on others but also their stage of disease. I usually ask them how they see their health changing over the next few months or year. Most will know that they are dying so then we can move on to conversations about care planning and death.'**

GP, North West England

## A national measure of end of life care services

The NHS has adopted the key performance indicator '[The percentage of deaths with 3 or more emergency admissions in the last 3 months of life](#)' to measure the quality of end of life care services.

From 2009 to 2018, the percentage of people with 3 or more emergency admissions in the

3 months before they died increased from 5.6% to 7.5%. This could indicate that there are issues with identification of people at risk of death, planning and availability of services, integrated urgent care response to unscheduled needs or communication, coordination and information sharing.

**‘Sometimes identifying a patient as being in their last year of life is opportunistic and relies on a GP either knowing a patient or taking the time to review their history. Unfortunately, time pressures mean sometimes seeing a snapshot isn’t enough. Fortunately, our chronic disease reviews through the nursing teams allow a more in-depth assessment.’**  
GP trainee

## Condition-specific identification of people approaching the end of life

The [Care Quality Commission’s \(CQC\) end of life care review](#) found that certain conditions, such as dementia, are not always recognised as life limiting. Because of this, people approaching the end of their life can often be identified at a late stage, with end of life care planning not always done effectively. The CQC found that healthcare professionals did not always consider the communication needs of people with dementia and sometimes assumed that the person with dementia lacked capacity. The CQC’s review found that only a third of people with dementia had a [mental capacity assessment](#).

## Personalised care planning

[NICE’s quality standard on end of life care for adults](#) says that the opportunity to develop a personalised care plan, which may include an advance care plan, should be part of a comprehensive holistic assessment for people approaching the end of life.

Advance care plans involve people making decisions about their future care with the help of health and social care practitioners. These plans can include:

- priorities and preferences for care and treatment
- decisions about resuscitation
- views about how and where they would like to be looked after in their last days of life
- who they would like to have with them
- any spiritual or religious beliefs they would like to be taken into account
- who they would like to make decisions for them if they become unable to make them for themselves.

## People with an advance care plan before their final hospital admission



([National Audit of Care at the End of Life](#), 2016 and 2019/20)

The [National Audit of Care at the End of Life](#) found that there has been an increase in advance care plans, but the latest audit still shows that 9 out of 10 people did not have one on arrival at their final hospital admission. Around half of people in their final hospital admission lacked capacity to make decisions about their care and may have benefited from an advance care plan.

A survey by the [Motor Neurone Disease \(MND\) Association](#) in 2019, observed that only 36% of people with MND were given the chance to make an advance care plan and less than half had the opportunity to discuss end of life issues. The [CQC report, A different ending: people with a learning disability](#), found that unidentified health needs among people with a learning disability can result in late recognition that they are at the end of their life, meaning fewer opportunities to plan their care.

## Coordination of care

[NICE's quality standard on end of life care for adults](#) says that people approaching the end of life should receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night. This should be delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.



**Care is well coordinated in the community, but there is room for improvement in how hospitals work with other services outside of the hospital.**

([National Survey of Bereaved People \[VOICES\]](#), 2016)

The [National Survey of Bereaved People \(VOICES\)](#) was completed by over 21,000 people in 2015. The survey reported that 83% of people who had a bereavement said community-based services, for example community nursing

and home care workers, worked well together during the last 3 months of the person’s life. This compares with 67% who said hospital services worked well with services outside the hospital, such as general practices.

**‘The Electronic Palliative Care Coordination System (EPaCCS) document is extremely useful and there is good communication between ourselves, the community nursing team and palliative care. However, it can take 24 to 48 hours for the EPaCCS document to be circulated and I have recently experienced it not reaching the ambulance service in time, resulting in an elderly patient who had a “do not attempt CPR” decision in place almost being resuscitated. Her daughter was understandably distressed by this.’**

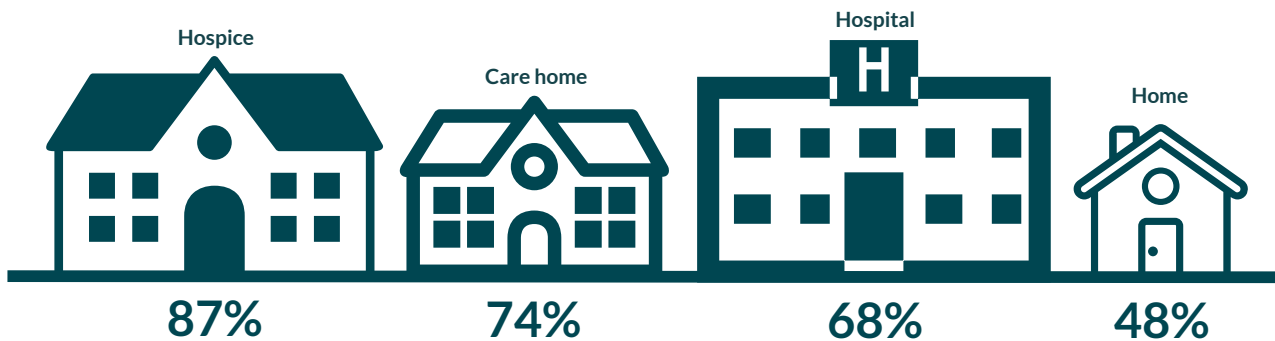
GP trainee

### Pain relief

[NICE’s quality standard on end of life care for adults](#) says that people approaching the end of life should have their needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

The [National Survey of Bereaved People \(VOICES\)](#) results suggested that pain relief was generally more readily available to people dying of cancer compared with people who had other conditions, such as cardiovascular disease. This may be because hospice care is mostly provided to [people who have cancer](#).

#### Achievement of complete pain relief (all or some of the time) across different care settings



([National Survey of Bereaved People \[VOICES\]](#), 2016)

**‘Once he was at home after surgery and chemotherapy he was not offered any community support. The GP had made it clear that his services would not be needed as the hospital would control everything. His pain control was poorly managed by the hospital with instructions to only take morphine if necessary at night. Without a clear pain and symptom control assessment clearly this was not going to achieve relief. He returned to hospital on numerous occasions due to intractable pain and vomiting.’**  
Friend of a bereaved wife

## Access to care settings

According to the [CQC’s end of life care review](#), people with conditions like dementia often face an additional barrier to dying in their preferred place because certain care settings, for example hospices, are not always offered as an option for them.



**Some hospices stated that they only accept patients with dementia who are ‘able to cooperate’.**

([CQC. A different ending: people with dementia, 2016](#))

## Insight from Marie Curie

There is a real need for data on patient and family experience of end of life care in order to understand where progress has been made and what gaps in care remain. The [National Audit of Care at the End of Life](#) should be extended to community settings to give us the richness of data that we have about end of life care in hospitals. The vast majority of people die in nursing or residential care settings and yet this is not reflected in the way that data is captured and portrayed.

It is likely that changes to commissioning of palliative and end of life care will focus much more on outcomes and encouraging providers to work together to offer more comprehensive and less fragmented 24/7 services. These changes would be widely welcomed.

Everyone should have access to good quality end of life care, wherever they access that care. There is an urgent need for services and their IT systems to work together, so that patients can transition seamlessly between services and have their plans and preferences follow them.

A good first step for many providers is education, allowing them to respond to the needs of all patients, especially those with comorbidities or non-cancer diagnoses. Effective communication and relationship building with the person and their family or social network is key. Person-centred interactions focused on ‘what matters’ to the person are fundamental and is the hallmark of being able to anticipate what is important to that person and what will make a difference to their overall experiences.

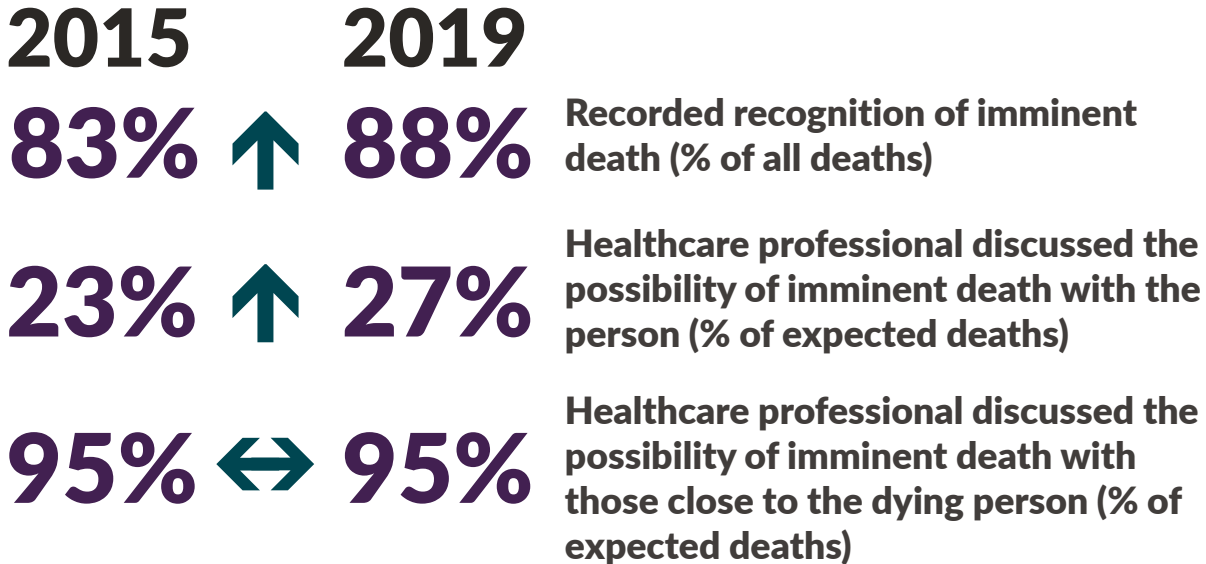


# Recognition and assessments in the last days of life

[NICE's guideline on care of dying adults in the last days of life](#) recommends that adults with signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering. As soon as it is recognised that a person may be entering the last days of life, the most appropriate team member should discuss this with the person and those important to them, unless they do not wish to be told.

Recognising and weighing up factors that may indicate someone is in their last days or hours of life is complex and can prove a difficult task, even for an experienced palliative care doctor.

## Recognition of and discussions about imminent death (death within days or hours)



([National Audit of Care at the End of Life](#), 2016 and 2019/20)

The [NICE guideline on care of dying adults in the last days of life](#) sets out the assessments that should be undertaken for adults in their last days of life, such as assessing mouth care, pain, breathing, nausea, agitation or delirium, anxiety and distress. These should be part of an individualised plan of care for the last days of life (see page 14).

Many of these symptoms can be debilitating and distressing for the dying person and those important to them. Identifying the underlying causes can help guide the course of treatment.

The [National Audit of Care at the End of Life](#) found that, over the last 2 audits, less than half of people who were dying received an assessment of their spiritual or religious needs, and just over half received an assessment of their emotional or psychological needs. People who were in their last days of life were much more likely to have an assessment of their physical health. However, the latest figures showed a decrease in some areas of physical assessment.

### Recorded health assessments in the last days of life, changes between 2018 and 2019



([National Audit of Care at the End of Life](#), 2019/20)

### Insight from Marie Curie

We know that in the acute care setting staff often recognise that death is imminent, but they do not always have conversations with patients about their options and preferences for end of life. Examples of good communication with dying patients from all settings, including community palliative care, need to be shared and replicated.

One way to improve this in the future is by having highly trained and well-supported volunteers. They can be 'companions' to patients who are dying in hospital who do not have relatives or friends with them.

A review of and ongoing support for training around communications with dying patients and

their families is needed to ensure that all people at the end of life have the option to talk about dying and their plans and preferences. We believe that compassionate conversations can provide a hopeful context and enable people to feel in control of what happens to them so that they can focus on living well until the end.

There is an emphasis on the physical needs of the patient, and further work needs to be undertaken to understand the barriers to providing emotional and spiritual care. The lived experience of people and their families is influenced by a holistic understanding of what is important and matters to that person.

# Shared decision making in the last days of life

The [NICE quality standard on care of dying adults in the last days of life](#) says that people in the last days of life and those important to them should be talked to and offered information in an accessible and sensitive way. The person who is dying should have opportunities to be involved in decisions about their care and to express their personal needs and preferences.



**In 2019, 79% of people close to the dying person said that staff communicated sensitively, a rise from 68% in 2018.**

([National Audit of Care at the End of Life](#), 2019/20)

Involvement of people close to the dying person in decisions about their care has remained static at just over 70% for the past 2 [National Audits of Care at the End of Life](#).

Good communication is crucial when a person is entering the last days of life. It allows the dying person and those important to them to prepare for death and make any necessary arrangements. The [More care, less pathway review of the Liverpool care pathway](#) highlighted many examples of poor communication, for example using euphemisms such as 'making them comfortable'. Poor communication at the end of life can lead to misunderstandings and unnecessary distress in people who are dying and those important to them.

## Discussions about risks and benefits

The [NICE guideline on care of dying adults in the last days of life](#) and [quality standard on care of dying adults in the last days of life](#) say that a discussion should take place about the risks and benefits of different hydration options. They also state that there should be an assessment of the medicines that may be needed to manage symptoms that often occur during the last days of life, such as agitation, anxiety, breathlessness, pain, nausea and vomiting. When medicines are prescribed in anticipation of symptoms, this is known as anticipatory prescribing. Anticipatory prescribing enables rapid relief of distressing symptoms.

The needs and preferences of the person who is dying should be discussed with the person, those important to them and the multiprofessional team caring for them.

Discussing options with the person who is dying, and those important to them, allows their wishes and preferences to be considered.

#### Discussions with the dying person about the risks and benefits of hydration options (% of expected deaths)



**10%** Had a discussion

**61%** Did not have a discussion because the dying person was unconscious or lacked capacity

**21%** Did not have a discussion and no reason was recorded

#### Discussions with the dying person about anticipatory prescribing (% of expected deaths)



**13%** Had a discussion

**69%** Did not have a discussion because the dying person was unconscious or lacked capacity

**15%** Did not have a discussion and no reason was recorded

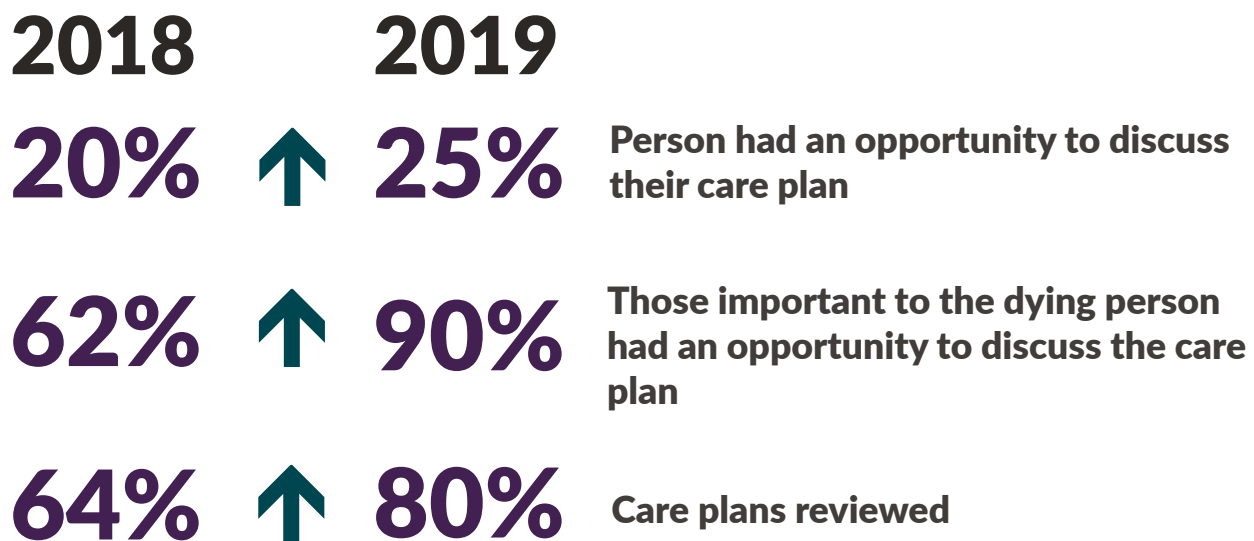
([National Audit of Care at the End of Life](#), 2019/20)

The 2019/20 [National Audit of Care at the End of Life](#) shows that many conversations could not take place because the dying person was unconscious or lacked capacity. Conversations between a healthcare professional and those important to the dying person happened more frequently. A conversation about the risks and benefits of hydration options was documented in 35% of records and a conversation about anticipatory prescribing documented in 60% of records.

## Individualised care planning

The [NICE guideline on care of dying adults in the last days of life](#) says that adults in the last days of life, and the people important to them, should be given opportunities to discuss, develop and review an individualised care plan for the last days of life. This is separate to the personalised care plan, which is made much earlier.

### Discussion and review of individualised care plans (% of all deaths)



([National Audit of Care at the End of Life, 2019/20](#))

The care plan should encompass the person's goals and wishes, preferred care setting, and current and anticipated care needs, including preferences for symptom management, maintaining hydration and care after death. Opportunities for discussion should continue so the plan can reflect any changes in the person's wishes or needs in the last days of their life.

Results from the [National Audit of Care at the End of Life](#) show that there has been an increase in individualised care plans for people in the last days of life, rising from 56% in 2015 to 65% in 2019.

## Preferred place of death

As part of the individualised care plan for the last days of life, [NICE's guideline on care of dying adults in the last days of life](#) says the dying person's preferred place to be cared for and to die should be discussed and recorded. However, it is not always possible for people to be in their preferred care setting and this should be explained as part of this discussion.

### End of life care rapid transport service

NICE says that systems should support smooth and rapid transfer between care settings for adults approaching the end of their life.

Planning transport for people in the last days of life can be very difficult given the unpredictable nature of a person's decline. A [shared learning example](#) describes how healthcare professionals were not always clear on who to call to arrange transport to a preferred place of death and often resorted to calling 999 in cases where there was a rapid decline in the persons health. As 999 calls are prioritised for treatment of the sickest people with potentially reversible causes, this often resulted in

delays in transport for the dying person. The Welsh Ambulance Services NHS Trust created a dedicated booking system for end of life care transport that was clear and understandable for all healthcare professionals. The system made use of the Non-Emergency Patient Transport Service and gave priority to end of life care journeys.

Since implementing the new service, average transport waiting times to the busiest hospice in the country have reduced by almost 2 hours. Evaluation of the service has provided positive feedback from healthcare professionals who say that it has improved end of life care.

[The National Audit of Care at the End of Life](#) found that there had been a small decline in the number of cases where there was documented evidence that the preferred place of death was indicated by the patient, from 28% in 2018 to just over 26% in 2019.

### Insight from Marie Curie

It is encouraging that most people close to the dying person said that staff communicated sensitively, but still a fifth of people did not have this experience. Improvements in discussions about hydration, anticipatory medications and care plans are also welcome but again there are significant gaps. Further improvement is needed in communication training and skills development for professionals across all care settings.

It is heartening to see that the audit has demonstrated improvement in the opportunities for patients and their families to discuss the plan of care for the last few days of life and that these plans are more regularly reviewed.

However, 75% of patients still have not had the opportunity to discuss their own individualised care plan in the last days of life, and further work is needed to ensure patients have the opportunity to discuss their preferences and wishes.

We are not surprised to see a slight reduction in focus on the preferred place of death, which can be difficult to achieve. Our preference is that the end of life experience is made as good as it can be, in whatever care setting, and that it should include 'what matters most' to the dying person. For example, it might be to see their dog for the last time, to hear their favourite music, or to know that someone will be with them when they are dying.

# Support for carers

Carers often have an important role in ensuring that their loved one receives a good standard of care. Carers who provide unpaid care and support to a family member, partner or friend are often anxious and physically and emotionally tired when the person they care for reaches the end of their life.

The [NICE guideline on supporting adult carers](#) recommends that carers should be identified in line with the [Care Act 2014](#) to ensure they receive information and support to enable them to carry out their caring roles.

[Hospice UK's organisational survey of carer assessment and support](#) found that 99% of hospices surveyed routinely identified the next of kin when people first accessed their services. A process or protocol for identifying main carers was reported in 87% of hospices, and 64% had a process for identifying additional carers.



**There have been recent improvements in the emotional and practical support provided by hospital staff, as well as sensitive communication.**

([National Audit of Care at the End of Life](#), 2019/20)

## Opportunities for discussion

[Our guideline on supporting adult carers](#) says that carers should be offered frequent opportunities for discussion and help to understand information about the diagnosis and prognosis of the person they care for (with the person's consent), and that these should be carried out in a sensitive manner.

Almost 70% of people close to a dying person felt they had enough opportunities to ask questions and discuss the dying person's condition, according to the 2018 [National Audit of Care at the End of Life](#), and 78% felt they were communicated with in a sensitive and compassionate way. Results of the 2019 survey suggest rates of sensitive communication have improved, with 84% saying staff communicated sensitively.

## Practical and emotional support

[NICE's guideline on end of life care for adults: service delivery](#) says that people managing and delivering services should think about what practical and emotional support can be provided to carers of adults approaching the end of their life and review this when needed.

According to the [National Audit of Care at the End of Life](#) there has been a slight increase in the proportion of people close to the dying person who felt they had enough practical support from staff, from almost 58% in 2018 to 62% in 2019.

## Support after the person dies

[NICE's quality standard on end of life care for adults](#) says that people closely affected by a death should be communicated with in a sensitive way and offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.



### Staff communicate sensitively, but availability of bereavement services can be poor.

([National Survey of Bereaved People \[VOICES\]](#), 2016)


Results of the 2018 [National Audit of Care at the End of Life](#) show that 82% of people who were close to the dying person felt supported by staff after the person's death. However, results of the [National Survey of Bereaved People \(VOICES\)](#) in 2016 showed that only 13% of people had the opportunity to talk to someone from health and social services or from a bereavement service about their feelings. Almost 21% said that they did not get an opportunity to talk to someone, but they would have liked to.

### Insight from Marie Curie

There is a need to understand the opportunities for assessing and meeting carers needs in all care settings, and in particular the needs of young carers. We suggest that a formal carer's assessment is fundamental. Many people don't recognise themselves as carers and miss out on opportunities to access support.

The emotional and physical burden on carers is immense and can impact on their own health and wellbeing. There is growing evidence of a long-lasting impact and legacy for carers after the person has died. Inadequate support and pre-bereavement care can have a serious impact on other aspects of their lives such as employment and social isolation.





We would like to thank Professor Bee Wee, National Clinical Director for end of life care; Julie Pearce, Chief Nurse and Executive Director of Caring Services at Marie Curie; Dr Sarah Holmes, Medical Director (Service Transformation and Innovation) at Marie Curie; Macmillan Cancer Support; and all those who contributed to this report.

Marie Curie provide free resources for [professionals](#) and the [public](#).

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