



Wirral

# Local End of Life Care Profile



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## Foreword

Last year in Wirral 3,891 people reached the end of their life.

At Marie Curie, we work hard to deliver services that support people with a terminal illness and their carers, fund research and campaign for the policy changes needed to deliver the best possible end of life experience for all. However, we know we can't deliver change alone. As a councillor, you have a significant role to play in ensuring that people living with a terminal illness in Wirral receive the best possible support.

In this local profile, we provide the facts, figures, policies, and practical resources to help you make a positive difference to the lives of people affected by dying, death and bereavement. We've also outlined a few steps that you can take during your term of office to make the lives of those

affected by terminal illness that little bit easier. We're keen to support you to deliver any of these recommendations – please contact the team at [local@mariecurie.org.uk](mailto:local@mariecurie.org.uk). If you adopt any of the measures outlined here – or have already done so – please do let us know so that we can share the good news with our supporters in Wirral.

Thank you for playing your part in ensuring everyone has the best possible end of life experience, both now and in the future.

**Yours sincerely,**

*Matthew*

*Matthew Reed, Chief Executive, Marie Curie*

# Why support for dying people matters and the role for local authorities

Everyone has the right to the best possible end of life experience, but the reality for too many people today falls far short of what we all hope for and should expect.

There is currently significant unmet need for palliative and end of life care. The most recent estimates suggest in England up to 25% of those who need palliative care are not receiving it. Applying national estimates to your local area this would equate to around 880 people in Wirral going without the care they need each year.

The Covid-19 pandemic highlighted how hard it is for some groups of people with a terminal illness and their families to get the care and support they need, including people who are living in poverty, alone, or with dementia – as well as people with learning disabilities, those experiencing homelessness or who are in prison, ethnic minority groups, and LGBTQ+ people.

The cost of living crisis is now doing the same, with poverty affecting more than 90,000 people each year at the end of their lives – including 19% in Wirral.

This is a key moment for action to improve palliative and end of life care. As a result of our ageing population, by 2043 it's estimated that 147,000 more people will require palliative care each year (a 25% increase).

New models for delivering care in the community will be needed to reduce pressures on the NHS, local government and social care and, where it's their preference, to support people to be cared for at home at the end of their lives. Larger numbers of families and carers will also require support through dying, death and bereavement.

Councils have a critical role to play in helping people to die well. Many of the core services that local authorities provide, such as social care, are important components of a high-quality approach to end of life care. Councils are also an important source of information and advice for residents, and as place-based leaders councils can help to play a convening role locally and work in partnership with other agencies and the wider voluntary sector. Councils up and down the country make a huge contribution to end of life care and have played a significant part in supporting local people in their final months of life.



# What is palliative and end of life care?

The World Health Organisation defines palliative care as the 'prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with

life-threatening illness. These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members'.

## Palliative care:

- entails early identification, assessment and treatment of these problems
- enhances quality of life, promotes dignity and comfort, and may also positively influence the course of illness
- should be integrated with and complement prevention, early diagnosis and treatment of serious or life-limiting health problems
- supports bereaved family members after the patient's death
- seeks to mitigate the pathogenic effects of poverty on patients and families and to protect them from suffering financial hardship due to illness or disability
- does not intentionally hasten death, but provides whatever treatment is necessary to achieve an adequate level of comfort for the patient in the context of the patient's values
- should be applied by health care workers at all levels of health care systems, including primary care providers, generalists and specialists in many disciplines and with various levels of palliative care training and skill, from basic to intermediate to specialist
- encourages active involvement by communities and community members
- should be accessible at all levels of health care systems and in patients' homes
- improves continuity of care and thus strengthens health systems.



# Health and wellbeing

## Key stats

- There were 3,891 deaths in Wirral in 2022
- Due to the ageing population, the number of deaths is projected to rise to 4,700 by 2043
- Each year, an estimated 880 people in Wirral do not receive the palliative and end of life care they need
- 5.90% of deaths were preceded by 3+ emergency admissions in the last 3 months of life in 2019 (England average = 7.1%)

For some time there has been a trend towards a higher proportion of people dying at home, meaning people with a terminal illness are increasingly reliant on health and social care services in the community. Acute pressures on GPs and district nursing services, workforce challenges in health and social care, and complex referral systems are making it extremely difficult for people to access the joined-up and local services they need.

Many people express a preference for being at home instead of hospital at the end of their life, yet too often are not able to have this preference met. People with a terminal illness often experience significant delays in having the assessment and funding put in place for the Fast-Track Continuing Healthcare they need in order to be discharged from hospital or remain in their own homes. This results in many people having to spend their final days and weeks in hospital.

Social care, delivered and commissioned by local authorities, plays a significant role in supporting people with palliative care needs or those at the end of life. Without this support people are unable to remain at home, get out of hospital, stay connected to their communities, live as well as possible before they die, or have the death they choose. Sadly, too many people miss out on this care. As a result, people often die in hospital when they would rather be at home. They also frequently use acute and expensive health services, such as accident and emergency and the ambulance service, which could be avoided if the right social care package was in place.

There is clear evidence that good quality end of life care in the community helps reduce unplanned

hospital admissions and the number of days patients spend in hospital. A&E visits and hospital stays are distressing for patients and their families, and also create significant pressures on NHS budgets. With around 5.5 million bed days taken up by people in the last year of life in England, the total cost of these admissions is currently estimated to be more than £1.2bn.

Following Marie Curie's campaign to Make End of Life Care Fair, the Government made a crucial change to the Health and Care Act, which means that, for the first time, palliative care services must now be provided by law in every part of England. This has placed a legal duty on the newly-formed Integrated Care Boards to commission palliative care services which meet the end of life care needs of their population – an important step to ending the postcode lottery in end of life care. However, research published in 2022 shows that of the 23 Integrated Care Systems that published strategies ahead of the Health and Care Bill entering Parliament, just six had identified palliative care as a priority area and only three identified measures of success relating to palliative care, such as reduced hospital admissions.

Marie Curie is urging Integrated Care Boards to ensure that the needs of people with a terminal illness and their carers are fully addressed in their five-year forward strategies and that they're fully compliant with NHS England's statutory guidance designed to help ICBs to deliver on their new statutory duty. We're also asking Local Authorities to use the influence their democratic legitimacy on the Integrated Care Partnership brings to ensure that palliative and end of life care receives the attention it deserves within the new Integrated Care Systems.

## The Ambitions Framework

The Ambitions Partnership 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 Ambitions Framework identifies 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 Councils have an important contribution to make in each of these areas.

## Recommendations

Local Authorities should:

- use their influence on the Integrated Care Partnership to ensure that the Integrated Care Board is meeting its new statutory duties relating to palliative and end of life care
- encourage the Integrated Care Board to ensure a fully accessible 24/7 palliative and end of life care (PEOLC) advice line is in place so that local people, as well as health and care professionals, know where to turn for specialist palliative care advice when they need advice and support
- undertake and publish a Joint Strategic Needs Assessment (JSNA) specifically for PEOLC to identify the current and future needs of the local population, which would give commissioners an accurate picture of local demand for services
- appoint an elected member End of Life Care Champion to raise the profile of end of life care across the council and with partners.

# Financial security

## Key stats

- 25% of people of working age and 18% of pensioners die in poverty in Wirral, compared to a UK average of 28% and 13% respectively
- 14% of households in Wirral were in fuel poverty in 2020 - before the first energy price cap increase in April 2022 (England average = 13%)

More than 90,000 people die in poverty in the UK every year, including 19% in Wirral. Those who die at working age are twice as likely as pensioners to die in poverty; one in four working age people who die are below the poverty line in their last year of life.

Many people experience poverty throughout their lives and continue to experience it as they reach the end of life. For many others however, the often devastating financial impact of terminal illness is what drives them into poverty – even if they were previously financially stable. A combination of income loss and additional costs after a terminal illness diagnosis can be as much as £16,000 per year.

Working age parents with children are particularly vulnerable to moving into poverty after a diagnosis of terminal illness. The impact on household income of one or both parents reducing or leaving work as a result of a terminal illness, alongside the cost of childcare, causes many working families to struggle financially. In fact, more than two in every five working age parents who die experience poverty in the last five years of life – which of course means that their children are experiencing poverty at the beginning of their lives.

There's also a substantially higher risk of experiencing poverty among people from minority ethnic groups than people from white ethnic groups, both in the general population and at the end of life. Among those in the last year of life in 2019, 43% of working age people and 27% of pensioners from minority ethnic groups were below the poverty line, compared to 25% of working age people and 13% of pensioners from

white ethnic groups.

**Nobody should die in poverty. While much social security policy is outside the control of local government, there are important steps that local authorities must take to support local residents who are experiencing poverty or who are at risk of falling below the poverty line.**

## Local families need your support now

Council Tax Support (also known as Council Tax Reduction) can be a lifeline for households on a low income or claiming certain benefits, providing support from the local authority towards some – or in some cases all – of the cost of Council Tax. Despite the particular risk of poverty faced by people of working age who have a terminal illness, many local authorities provide only limited support to those under State Pension age.

Similarly, Discretionary Housing Payments can be a vital source of support for households struggling to meet their housing costs due to either the Removal of the Spare Room Subsidy (RSRS, the 'bedroom tax') or if the Local Housing Allowance (LHA) is insufficient to meet their rent. As with Council Tax Support, however, eligibility criteria for Discretionary Housing Payments vary across the country and there is no requirement for local authorities to consider whether a person is terminally ill before deciding whether to make a payment. Given that people living in rented accommodation are at particular risk of falling into poverty at the end of their lives, councils should ensure those nearing the end of life are duly prioritised for support with their housing costs.

As result of disabilities caused by their condition, people living with a terminal illness may need adaptations to their home to enable them to continue living there. Schemes like the Disabled Facilities Grant (DFG) provide financial support towards the cost of these adaptations. However, the means test to determine eligibility for a DFG considers income and assets but does not consider outgoings. This fails to account for the real costs of living with terminal illness, while the means test thresholds themselves have not kept pace with inflation and housing costs. In practice, this means many people living with a terminal illness are denied the financial support they need to make their home accessible.

Local authorities in England can also support local residents at risk of fuel poverty and the health impacts of living in cold housing. The

National Institute for Clinical Excellence (NICE) has issued guidance which makes a number of recommendations to Health and Wellbeing Boards (HWBs) in England. However, our research has shown implementation of the NICE NG6 guideline is patchy, with 40% of HWBs in England not having a cold homes strategy in place and nearly half not having a single-point-of-contact referral service. People living with a terminal illness and those nearing the end of life are particularly vulnerable to fuel poverty. As energy prices rise, many more terminally ill people are at risk of falling below the poverty line as a result of spiralling energy costs and the health impacts of living in cold homes. Improving compliance with NICE's NG6 guidelines will ensure local authorities are doing all they can to support people living with a terminal illness who are at risk of fuel poverty.

## Recommendations

Local Authorities should:

- review their eligibility criteria for Council Tax Support to ensure that people living with a terminal illness and their family carers are eligible, irrespective of age or savings
- prioritise people living with a terminal illness when allocating Discretionary Housing Payments
- consider the outgoings, as well as the income and assets, of applicants for Disabled Facilities Grants and fast-track the process and payment of grants
- use their leadership role on Health and Wellbeing Boards and Integrated Care Systems to ensure that these bodies audit their compliance with NICE's NG6 recommendations.



# Inequalities and inequities

Profound and persistent inequalities exist in access to, and experiences of, care and support for people affected by dying, death and bereavement. Given the unique position and local insights they hold at place-level, local authorities have a key role to play in tackling inequity at the end of life.

Groups and communities experiencing wider societal disadvantage, often at multiple intersections, are disproportionately represented among those without access to quality palliative and end of life care (PEoLC). These include, but are not limited to:

- **People with conditions other than cancer**  
Existing healthcare treatment pathways for cancer are often well-placed to recognise the condition as potentially incurable, enabling the management of associated PEoLC needs. By contrast, people with non-malignant conditions are less likely to be able to access PEoLC.
- **The oldest old, i.e., people aged 85 years or over**  
Most people die above the age of 80 and from chronic and degenerative diseases, yet people over the age of 85 are less likely to access palliative care than people below the age of 85.
- **Racialised, minoritised ethnic communities**  
Unmet need for PEoLC among racialised communities is stark. Health inequalities exist between minoritised ethnic and white groups, and between different minoritised ethnic groups, presenting a complex picture affected

by deprivation, environmental, physiological, behavioural and cultural factors.

- **People living in rural or more deprived areas**  
Rural and more deprived areas are underserved by some PEoLC services compared to urban centres and more affluent areas.
- **People with learning disabilities**  
Delivering PEoLC support can be more complex due to difficulties with cognition, understanding and communication, challenges in decision making processes, co-morbidities, and mental health issues.
- **Imprisoned people**  
There are significant shortcomings regarding imprisoned people's PEoLC including inequivalent care when compared to the wider community, inappropriate use of restraints, and absence of consideration of early release despite imminently facing the end of life.
- **LGBTQ+ communities**  
The exposure of LGBTQ+ people to health inequities is well documented within and beyond PEoLC. Good PEoLC is made impossible when fears (both experienced and expected) of discrimination and a presumption of heteronormativity shroud such interactions. For trans and gender diverse people, there have been reported instances of insensitivity from staff, such as misgendering, confusion over their identity, and instances of poor physical care.

## Recommendations

Local Authorities should:

- use their influence on the Integrated Care Partnership to ensure that the Integrated Care Board is meeting its new statutory duties relating to addressing and tackling health inequalities over the whole life course, including at the end of life
- ensure that an inequalities lens is embedded while conducting their Joint Strategic Needs Assessments, providing commissioners with an understanding of the local unmet healthcare need for disadvantaged groups over the whole life course, including at the end of life.

# Support for carers

## Key stats

- 33,503 people in Wirral care for a family member, friend of neighbour because they have long-term physical or mental health conditions or illnesses, or problems related to old age
- Across England, just 25% of carers report having had a carer's assessment or re-assessment in the last 12 months

Carers play a pivotal role in providing vital unpaid support to a family member or friend with a terminal illness, often doing so through to the end of that person's life. This caring role is extensive, varied and in many cases around-the-clock. Support includes tasks like housework or shopping, personal care like dressing and washing, and emotional support.

Carers of people with a terminal illness are often older and have to manage the physical demands that caring places on their own health, at the same time as the impact of ageing. The demands of caring can have a significant impact on a carer's physical health, leaving them at increased risk of illness and injury.

Looking after someone with a terminal illness can be a mental and emotional rollercoaster. Receiving news of a terminal illness diagnosis can be

devastating and carers can experience feelings of fear, anxiety, and uncertainty about the future.

Despite the critical role that carers play and their huge contribution in supporting our social care system, the support available to them often falls short of what's needed. 76% of bereaved carers surveyed by Marie Curie felt they were not offered all the care and support they needed as carers during the Covid-19 pandemic.

Under the Care Act 2014, carers are eligible for a formal assessment of their needs by their local authority, but only around a third of carers of a person with palliative care needs report having had an assessment done or reviewed in the past 12 months. The quality of assessments is also variable, with vital issues such as respite care and support with their own needs often not addressed.

## Recommendations

Local Authorities should:

- ensure every carer of someone with a terminal illness is offered a carer's assessment at least annually and that recommendations are acted upon promptly and fully
- ensure that Councils' carers' strategies include a specific focus on carers of people with a terminal illness and include support through bereavement



# Bereavement support

## Key stats

- There were around 19,460 bereavements in Wirral last year
- Across the UK, over 40% of adults who want formal bereavement support don't receive any, while half of bereaved children said they didn't get the support they needed from their schools and colleges

Bereavement can be an exceptionally isolating and lonely experience, however almost everyone will experience a bereavement at some point in their life. While most people can be adequately supported by their friends, families and wider communities through a bereavement, some adults, children, and young people will also need more formal emotional support, whether from a peer support group, a volunteer, or a professional therapist.

In 2022, the UK Commission on Bereavement carried out one of the largest ever consultations on bereavement support, which included more than 1,000 adult and 100 child respondents to the surveys and evidence submitted from more than 130 organisations. It found that bereavement support needs to be more accessible; a lack of guidance and difficulty finding the right information about what to do after someone dies means that many bereaved people feel unsupported and lost. Furthermore, there's no legal right to take paid time off for bereavement, except parental bereavement leave for a person whose child has died, and many employers offer little or no additional bereavement support.

The Commission also highlighted that families can wait a long time for a funeral in some localities. Delays to funerals can be particularly upsetting for those bereaved families whose faith requires a swift burial, such as the Jewish principle of honouring the dead (k'vod hamet) and the Muslim custom of burying the dead promptly. Out of hours systems to enable the rapid processing of death paperwork necessary for burials to happen quickly,

which are available in some but not all local authority areas, can help.

The high cost of funerals, cremation and burials is another concern, particularly for those in poverty, and those who experienced sudden, unexpected deaths. Many people are not eligible for bereavement benefits or find them insufficient to cover costs. The Commission also heard of difficulties some people experience in attempting to access public health funerals, in addition to some instances of stigma and hostility towards bereaved people seeking to access them. Public health funerals are provided by local authorities for people who have died when no one else is making the necessary arrangements for a funeral. There is a statutory duty on local authorities to arrange for a burial or cremation where no suitable alternative arrangements are being made, however, there is considerable variation in how these funerals are delivered across the country.

The Commission also found that for people living in social housing, a bereavement can also bring the profound worry and disruption of an immediate eviction notice. Some grieving people living in social housing receive an eviction notice and face the strain of having to find somewhere to live, or even the threat of homelessness, through no fault of their own. Some people living in social housing lose the right to stay in their home because succession of the tenancy agreement doesn't pass on to them and currently, they could face eviction within as little as four weeks. This is most common with adult children living with their parents. Others face eviction due to being told



their home is now too big for their needs. However, downsizing can be difficult, as there may not be any suitable properties available in the same area – particularly challenging for families with children who may need to stay close to schools and support networks. People who shared evidence with the UK Commission on Bereavement described how having to leave the family home, with all its memories, compounded feelings of distress – especially so soon after the death.

Ensuring individuals and families are properly supported through bereavement also depends on tackling taboos and encouraging more open conversations about death and dying, helping to enable communities to adopt a compassionate

approach to supporting bereaved people of all ages. That's why we're calling on Local Authorities to harness the resources and compassion of local people by embedding Compassionate Communities in their local areas. Compassionate Communities is a social movement where local people support others who are affected by dying, death and bereavement. They are networks of volunteers that work alongside formal services. For example, a local person might volunteer to do food shopping for a neighbour who can't leave the house, or provide companionship to someone living alone with a terminal illness. This support can make a huge difference to the person who receives it, while complementing the work of formal palliative care services.

## Recommendations

Local Authorities should:

- review their policies and procedures relating to public health funerals to ensure that all people looking to access such funerals are able to do so in a dignified manner
- in their role of social landlord, allow a six-month grace period for evictions after a bereavement
- encourage schools and local employers to adopt a bereavement policy to ensure that people are supported through bereavement at school and at work
- embed a Compassionate Community approach in their area to complement the work of formal bereavement services
- ensure out of hours systems are in place to enable rapid processing of death paperwork and registrations so that quick burials can take place for people whose religion requires it.

# Summary of recommendations

## Health and wellbeing

Local Authorities should:

- use their influence on the Integrated Care Partnership to ensure that the Integrated Care Board is meeting its new statutory duties relating to palliative and end of life care
- encourage the Integrated Care Board to ensure a 24/7 palliative and end of life care support line is in place so that local people, as well as health and care professionals, know where to turn for specialist palliative care information and support when they need it
- undertake and publish a Joint Strategic Needs Assessment (JSNA) specifically for PEOLC to identify the current and future needs of the local population, which would give commissioners an accurate picture of local demand for services
- appoint an elected member end of life care champion to raise the profile of end of life care across the council and with partners.

## Financial security

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## Inequalities and inequities

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Care Board is meeting its new statutory duties relating to addressing and tackling health inequalities over the whole life course, including at the end of life

- ensure that an inequalities lens is embedded while conducting their Joint Strategic Needs Assessments, providing commissioners with an understanding of the local unmet healthcare need for disadvantaged groups over the whole life course, including at the end of life

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Local Authorities should:

- ensure every carer of someone with a terminal illness is offered a carer's assessment at least annually and that recommendations are acted upon promptly and fully
- ensure that Councils' carers' strategies include a specific focus on carers of people with a terminal illness and include support through bereavement

## Bereavement support

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## About Marie Curie

Marie Curie works hard to support dying people and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives. Our free information and support services give guidance and support to families. We're the largest charitable funder of palliative and end of life care research in the UK and campaign for the policy changes needed to deliver the best possible end of life experience for all.

For further information or discussion on any of the issues covered in this briefing, please don't hesitate to contact us at [local@mariecurie.org.uk](mailto:local@mariecurie.org.uk)

## We're here for you with the support you need, when you need it

Call the Marie Curie Support Line for practical or clinical information and emotional support if you're living with or caring for someone who has a terminal illness, whatever your situation.

You don't need to have used Marie Curie services or be directly involved in a loved-one's care to call the support line. We're here to help family and friends, and you can find support on a wide range of issues. No one is turned away, so please do not hesitate to call if you need any kind of support.

If you feel you'd benefit from speaking to one of our Information and Support Nurses, please do call our Support Line on **0800 090 2309** and we can arrange a call back for you.

We also have Energy Support Officers who can provide dedicated information, support and practical guidance on the cost of energy bills for people affected by terminal illness. This includes information on benefits, supplier-specific support, grants and energy efficiency updates.

Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit our website [mariecurie.org.uk](https://mariecurie.org.uk)