Marie Curie

70 years of end of life care in the community

Supported by

Qni The Queen's Nursing Institute

Contents

Foreword

When it was published in 1952, the joint report by Marie Curie and the Queen's Nursing Institute (QNI) "on a national survey concerning patients with cancer nursed at home" was a milestone in evidence, policy and practice in 20th century end of life care.

The 1952 data was collected in a time of great change, following the second world war and the flu epidemic of 1951. Despite – or perhaps because of – this, the report, and others like it, were seen as a key opportunity to reconceptualise the way people at the end of life were treated in Britain. The ideas that emerged at this time were key to the development of the hospice movement – and the palliative and end of life care (PEoLC) sector that we see today.

Fast forward to now, just over 70 years later, and the UK is once again in flux, following the Covid-19 pandemic, and with the ongoing cost of living crisis. We fervently hope that – just as the original report did in 1952 – this report will act as a catalyst for much-needed transformation in how we care for people at the end of life.

Importance of partnership working

This report is a partnership between Marie Curie and the QNI. Partnership working is essential for good end of life care – many people and different organisations are involved in co-ordinating care at end of life. And by working together at all levels, with sufficient resources, we can ensure that all individuals at end of life, and those close to them, can have the best possible end of life experience.

Evidence-informed influencing has been imperative to Marie Curie's work since its inception in 1948. Likewise, the QNI has always relied on evidence and data and this approach underpins its strategic priorities. Florence Nightingale, one of the charity's founders, was herself a leading statistician as well as a nursing pioneer, and the QNI continues in this spirit.

Addressing the persistent challenges described through this report will require partnership working between statutory services, the voluntary sector and private enterprise. With an age demographic now fundamentally different to that of the 1950s, this partnership working will be vital if we are to meet the growing demand for PEoLC in the UK over the coming decades.

All organisations involved in healthcare and social care provision have a role to play in this work, and the messages of this report apply to us all.

> **“Now, as in 1952, too many people are dying at home without the care and support they critically need – particularly outside normal ‘business hours’ And far too many dying people are still facing severe poverty and deep social isolation.**

Why is it important to revisit this work?

Despite transformational change across society over the last 70 years, there are many persistent and pernicious issues affecting end of life care today. Now, as then, too many people are dying at home without the care and support they critically need – particularly outside normal "business hours". And far too many dying people are still facing severe poverty and deep social isolation at the end of their lives.

Shockingly, despite 70 years of increased wealth, benefits reform, an expanded NHS and medical advances, this research has drawn the same overall conclusion as the 1952 report: that "considerable hardship exists" for many at the end of their lives.

It is impossible not to be taken aback that, in 21st century Britain, over half (58%) of respondents said they had cared for people for whom a food bank would be helpful, with 7% saying that at least half the people they cared for need a food bank. In 2023 it is unacceptable that so many people at the end of their lives are still facing the stark impact of poverty.

It is the ambition of Marie Curie and the QNI that this sobering report will be a catalyst for change. Such change must not be piecemeal. It is clear from this research that systemic changes are needed to address the complex and sustained challenges that undermine society's ability to ensure good care for those at the end of their lives. Tackling these deep-seated challenges requires co-designed services tailored to meet local and individual needs, evidence-informed and innovative solutions, and a committed focus on equitable, holistic, personalised care and support for everyone affected by dying, death and bereavement.

How we treat dying people is a key marker of a civilised society.

As the UK's leading end of life charity, Marie Curie is committed to driving change to improve the end of life experience for all, whatever the illness. And the QNI, as the leading professional organisation for community nurses, sees nurses with specialist skills and knowledge, working both in hospices and in the home, at the centre of this shared vision. Together, we hope this research will help guide the way to realise the changes needed and improve end of life care for all.

We would like to thank everyone who circulated and responded to the survey.

Matthew Reed
Chief Executive
Marie Curie

Dr Crystal Oldman CBE
Chief Executive
The Queen's Nursing Institute

Executive summary

In 1952, the Marie Curie Memorial Fund and the Queen's Institute of District Nursing (as the two organisations were then known) conducted a survey to understand the needs of patients with advanced disease being cared for at home. Since then, the world has changed considerably, but there are striking parallels. In particular, financial hardship and the impact of widespread infectious disease, the Covid-19 pandemic now and the 1951 flu epidemic then.

In 2022, we carried out another national survey with end of life care providers to consider what palliative and end of life care (PEoLC) in the community looks like 70 years on. Once again the QNI supported the research, with survey development, promotion and analysis.

We know too many people aren't getting what they need. Despite obvious improvements in healthcare delivery, the end of life care system hasn't kept pace. The need for holistic end of life care – where and when people need it – is outstripping the capacity to deliver it. This can have long-lasting detrimental effects on everyone involved.

Comparing insight and experiences from the two surveys is an opportunity to reflect both on what has changed over the last 70 years, and on what needs to change with respect to the social condition of dying at home, and achieving equity of end of life experience. This report provides new insight and evidence to underpin actions to address old and new challenges.

PEoLC providers unable to fully meet needs

Nine out of ten respondents to this latest survey reported being unable to meet patient or carer needs, at least in part. Often, this was because health and social care professionals lacked time to provide holistic PEoLC in the way they wanted. This is leaving many care providers frustrated and burnt out. And unpaid carers aren't getting the support they need to care for others or themselves either.

Added to this, most carers in 2022 reported that a significant number of the people they see experience financial hardship, loneliness and isolation, whether geographical or social.

Through 70 years of research and innovation, we've learned more about the needs and experiences of people at end of life and those close to them. We understand there are more people, with more complex needs, who we should be helping. We also know people from particular marginalised communities face more barriers to accessing services.

> “Comparing recent experiences with those of 70 years ago is an opportunity to focus on what needs to change to achieve equity of end of life experience.

In 1952, most people at the end of life were cared for by relatives, because paid care was financially prohibitive and the NHS didn't offer overnight nursing. Now, there are more formal PEoLC providers than ever – but the needs of people at end of life still aren't being met.

One in six respondents reported that out of hours support was mostly or always insufficient. This creates multiple challenges – from junior staff having to make complex decisions in the absence of senior practitioners, to patients left in pain or with unmet hygiene needs, resulting in added stress and poor psychological health. Today, as in 1952, inadequate care packages mean much support is being left to unpaid caregivers.

Financial hardship remains a serious challenge

It's deeply wrong that despite the UK becoming considerably wealthier over the past 70 years, financial hardship is still widespread at the end of life. This not only creates additional stress for patients and families at an already challenging time, but it also forces people to take drastic actions with potentially serious consequences for their health. Over half (58%) of respondents saw people for whom a food bank would be helpful at least some of the time. And shockingly, 7% said that at least half the people they care for need a food bank. Community nurses also reported families living in cold homes or turning off oxygen machines to reduce heating and electricity bills.

More than half of respondents said they regularly cared for people with difficulty accessing appropriate housing, benefits, equipment, medication, information or transportation. More than one-third said their patients' financial hardship negatively impacts their physical health, and more than one in five said it affects their quality of life, leading to social isolation.

Social isolation a common experience

Feelings of isolation are worryingly common, with 97% of respondents caring for people at home who are experiencing loneliness at the end of life. While most respondents believe alleviating social isolation is part of their role, more than three-quarters reported they often don't have time to offer such support. It is concerning that people experiencing isolation, whether geographical or social, are still not having equitable end of life experiences. Almost nine out of ten respondents are caring for people who live alone. And often, these patients are not having their wishes met regarding their place of death.

People living rurally need more support than those in urban areas to access care and services that can enable them to spend more of the final phase of life at home. And there are also likely to be fewer local health, social and out of hours care services, meaning a need to travel significant distances for essential support.

Yet, virtually all (99%) respondents feel they care for people whose needs *could* be met within their communities. Respondents acknowledged the importance of having local, up-to-date knowledge of community support organisations to which they can signpost patients and those close to them.

Our recommendations for improving palliative and end of life care

It's critical to get palliative and end of life care (PEoLC) and support right for patients and families, whenever and wherever they need it, whatever the illness. Marie Curie is calling for four key changes.

- **A new funding solution for hospices and PEoLC** – to end the postcode lottery in access, reduce reliance on charitable donations, and ensure services are fit for the future.

- **A national PEoLC strategy, supported by a delivery plan, in every nation** – to include 24/7 access to care, through a single point of access, offering advice, guidance and support in every local area; as well as improved access to medicines.

- **An end to poverty among people at the end of life** – including by ensuring that those of working age can claim their State Pension and other pension age benefits; and protecting everyone living with a terminal illness from high energy costs through targeted support.

- **A new deal for families and carers of people living with a terminal illness** – including better identification and needs assessments for carers, and improvements in financial and bereavement support.

Introduction: end of life care – 70 years on

When the NHS was born in 1948, despite a vision of healthcare 'from the cradle to the grave', care for the dying was largely overlooked. There was scant reference to end of life care (EOLC) in the NHS Act of 1946[1]. The changing perception of death from social or cultural event to medical one, the focus on curative treatment, and the taboo around talking about death and dying may all have contributed to this.

In the 1950s, many more people were dying in hospitals than in their own homes, due to the availability of new treatments; death, therefore, was often seen as a failure by medical professionals.

Modern approaches to the delivery of EOLC as part of the welfare state only began to take hold through the 1950s and 1960s – with lasting consequences for the state of care and the development of services.

Two pivotal reports published during the 1950s played a transformative role in shifting the conversation around care for people at the end of life[2]. The first, published in 1952 by the Marie Curie Memorial Fund (now Marie Curie) and the Queen's Institute of District Nursing (now the Queen's Nursing Institute, the QNI), described the needs of people with cancer who were dying at home and made recommendations about the best methods of support[3]. The second, published

Figure 1. Marie Curie – key milestones in the provision of palliative care since 1948

1948

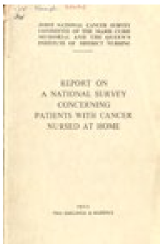
The National Health Service Act comes into effect on 5 July 1948. The Marie Curie International Memorial is formally established the next day.

1950-1960

During the 1950s and early 1960s, the charity opens ten Marie Curie Homes in adapted buildings

1952

A joint report is published with the Queen's Institute for District Nursing. The first Marie Curie Hospice opens in Fife, Scotland, and the first research grant is awarded.



REPORT ON
A NATIONAL SURVEY
CONCERNING
PATIENTS WITH CANCER
NURSED AT HOME

1958

Following the 1952 report, Marie Curie begins running its own day and night nursing service.

1960-1980

In the 1960s, Marie Curie Homes are purpose-designed and built, beginning with Belfast in 1965.

1967

St Christopher's, the first "modern hospice" (see page 9) opens.

in 1963, was a study of the physical and mental suffering of the dying[4].

Around the same time, concerned medical professionals were increasingly recognising the importance of specialist care for the dying[5]. This was driven by Dame Cicely Saunders, who developed the fundamental concept of “total pain”. Through her pioneering work, the first “modern hospice” (combining expert pain and symptom control, compassionate care, teaching and clinical research) was established – St Christopher’s in South London.

Through the 1960s, hospices began to open across the UK – and there are now around 200, providing care for people with all terminal illnesses. Yet still today, around two-thirds of the approximately £1.5 billion spent on specialist palliative care services in the UK each year comes from charitable donations[6] – a profound anomaly for a core area of health provision.

As the timeline in Figure 1 illustrates, it took until 2022 for the commissioning of palliative care to become an explicit legal requirement in every part of England[7]. In Scotland, Wales and Northern Ireland, there remains no explicit requirement in legislation to deliver palliative care. Instead all three nations have policy, guidance and reporting requirements with varying importance and impact.

1974

The term “palliative care” is coined. Responsibility for community care in England and Wales passes to the NHS. At this point, Marie Curie negotiates a 50:50 sharing of costs for the service in England and Wales with the NHS.

1980s

Marie Curie Homes (later Marie Curie Hospices) move away from providing long-term nursing care to cancer patients and become increasingly focused on hospice care.

1990s

Marie Curie begins to carry out pioneering palliative care research – investigations are focused on improving care for people approaching the end of their lives.

2004

Marie Curie launches its first national campaign: “Supporting the choice to die at home”.

2014

Marie Curie changes its name to recognise support for people living with any terminal illness.

2022

The Health and Care Act introduces the first explicit legal duty to commission palliative care in England. Marie Curie and the QNI partner again to conduct a national survey of community end of life care.

Why revisit the 1952 survey?

As the publication of the influential 1952 report illustrates, collaborative research to influence policy and practice has been at the heart of Marie Curie's work since its inception in 1948. In 2022, 70 years after the report's publication, Marie Curie and the QNI partnered again to conduct further research. And in this report we revisit the work done in 1952, alongside the 2022 research, and consider what palliative and end of life care in the community looks like now.

The 1952 survey highlighted that unmet needs could be met by hospice and nursing services at home. Yet, 70 years on, one in four people aren't getting the care and support they need at end of life[8], despite rapid growth in the delivery of palliative care. Importantly, the 1952 survey focused not only on nursing care, but also on the social condition of dying in the early 1950s – in other words, the impact of social, economic and political conditions on the experience of ill health[9]. It felt timely to revisit this 70 years later, particularly given that the 1952 survey was conducted shortly after the 1950/1951 flu epidemic.

The report states:

> **"As a result of the experience in the medical and nursing professions, and in varied branches of public service, the members of the Joint Committee have personal knowledge of the serious social problems caused by a disease which in 1950, in the British Isles alone, was certified as having brought about the death of 95,000 people and attacked many more."**
> **1952 report, page 9**

In 2020, Covid-19 was mentioned as the primary or a contributory cause of death for around 77,000 people across the UK[10]. Post-pandemic there's been a significant and sustained rise in the number of people dying at home. 1952 and 2022 were both shaped by the repercussions of widespread disease, making this comparison of PEoLC particularly relevant and poignant.

In a further similarity, the 1950s saw the UK in economic recovery after the second world war. Sugar, cheese and meat were still rationed at the time of the 1952 survey[11], and around one in ten people lived in poverty[12]. In 2020/21, the equivalent figure was around one in five, making this work particularly timely[13].

A closer look

Marie Curie – contribution to end of life care

Marie Curie is the UK's leading end of life charity, with a 75-year history (see Figure 1). The first Marie Curie Home was established in Fife, Scotland, in 1952. Nine further homes were opened through the 1950s and 1960s, in all four UK nations, in response to the 1952 report to provide residential care for people with cancer. And in 1958 the organisation, then called the Marie Curie Memorial Foundation, began to provide day and night nursing, at home.

Reflecting its support for people living with any terminal illness, the organisation's name was shortened to Marie Curie in 2014. Provision continued to grow over the subsequent decades (see Figure 1). In 2022-23, 44,200 people were cared for by Marie Curie Nurses and healthcare assistants; 901 households were supported by Helper volunteers; and over 1.4 million people accessed online and printed information and support materials[14].

Queen's Nursing Institute – contribution to community care

Like Marie Curie, The Queen's Nursing Institute has a rich history. It is the oldest professional nursing organisation in the UK, dating back to 1887. The QNI operates in England, Wales and Northern Ireland, with QNI Scotland as a separate organisation. Until the 1960s, the core function of the organisation was to organise the training of district nurses. Today, the QNI is a registered charity dedicated to improving the nursing care of people living at home or in the community. The charity promotes excellence in care by setting national standards of specialist nursing education and practice[15].

Person and family-centred, high-quality end of life care is a fundamental part of the work of many of the community nurses in the QNI's networks, particularly nursing teams and those with a palliative care specialism. Queen's Nurses work across community care settings and the QNI's nurse-led innovation projects share knowledge and best practice to help introduce new models of evidence-based care.

A closer look

District nursing in the 1950s

In the 1950s, district nurses were part of the National Health Service and employed by local authorities. Until 1948 they had been employed by District Nursing Associations; these were independent voluntary organisations funded locally from various sources, including patient contributions. Most district nurses had undergone the training programme developed by the QNI and were given the title Queen's Nurse. There was also a national uniform and insignia for all Queen's Nurses, making them recognisable in the community.

District nursing was therefore already a national service with its own identity when it was adopted into the NHS.

District nurses in the 1950s worked closely with GPs and had wide-ranging responsibilities. They helped plan public health, promoted good hygiene and nutrition when visiting people in their own homes, and attended emergency call-outs as first responders. They had a major role in the management of long-term health conditions, particularly for those living alone at home who were frail or lacking mobility.

Looking to the future

We're currently at a critical juncture for considering care and support for people living with a terminal illness.

Estimates show that up to 90% of people who die in the UK could benefit from palliative care – that's more than half a million people[8]. And with an ageing population across the UK, that need is expected to grow rapidly in the coming years. By 2048, the number of people needing palliative care each year is expected to increase by more than 147,000.

At the same time, the nature of the PEoLC needed is likely to be more complex as the UK population ages and the proportion of people with multiple chronic and life-limiting health conditions increases. Importantly, there is unequal access to hospice PEoLC for particular groups – patients with illnesses other than cancer, frail older people, those from minoritised ethnic groups and those living in rural or deprived areas. This emphasises the importance of community-based PEoLC provided by non-specialists[16].

90%

Up to 90% of people who die each year in the UK could benefit from palliative care – more than half a million people.

Currently no part of the UK has a plan that could adequately address this scale of rising need. With a model for funding the sector that relies heavily on charitable donations, PEoLC is facing serious challenges.

However, as in the early 1950s, the needs of people at end of life are once again coming under scrutiny. This is exemplified by the UK Government introducing – for the first time in the history of the NHS – an explicit legal requirement to commission palliative care in England.

Marie Curie's commitment to influencing and shaping the end of life system makes us ideally placed to move the conversation forward once again – to focus on what needs to change with respect to the social condition of dying at home now, 70 years on.

This report gives new insight and evidence to support actions to tackle these challenges, both pre-exisiting and new.

2. What did we do?

Replicating the methodology and questions used in the 1952 report was not appropriate for numerous reasons. Firstly, Marie Curie now supports people with all terminal conditions, not just cancer. Secondly, care and support for those dying at home today involves many professionals rather than only district nurses. Thirdly, patient and data privacy concerns have changed since the 1950s, and the present survey needed to ensure privacy was carefully protected.

We therefore needed a new approach that addressed these issues and facilitated meaningful comparisons with the data from 1952. To accomplish this, we conducted a thematic analysis of the 1952 report itself to reveal the key themes. We conceptualised these key themes and developed our survey around three research questions.

1

What end of life care and support is delivered in patients' homes and by whom?

2

What is the social condition of dying at home?

3

How do people's relationships, social and community engagement affect their end of life experience?

We developed 60 questions for the survey, which generated a mix of quantitative and qualitative data [see Appendix, p42]. The survey was hosted on a digital platform. It began with a brief explanation of the 1952 work and why it was being repeated, with further participation details to support informed consent. To ensure the survey worked smoothly, and that the consent procedures and digital distribution methods were clear, we piloted the survey with a small varied sample of health and social care professionals.

We conducted quantitative analysis using the statistical software programmes SPSS[17] and RStudio[18]. For free text responses, we developed a coding framework for each question, based on emerging themes, and analysed the responses.

We approached the analysis iteratively, and additional quantitative analyses were conducted when we identified themes of interest in the qualitative analysis.

Limitations of the approach

When reading the results of this survey and its implications, it's important to consider which viewpoints and accounts are reflected in the data from this self-selecting, convenience sample.

Respondent population
The data in our 2022 report reflects only the views of paid professionals and formal volunteers. We did not approach any patients or their families, friends or unpaid caregivers.

We recognise the invaluable PEoLC and support provided by unpaid family caregivers, friends and neighbours. There is rightly much research dedicated to better understanding their experiences and needs, but there is a notable research gap about the care provided by paid professionals and volunteers in people's homes.

The survey also applied only to those who support adults dying at home, as the 1952 report only considered adults. The care of children and young people at the end of life often involves different support organisations to adult services and we felt it would not be appropriate to pool findings about support received by children and young people, with those about adult services.

Location
The responses are limited to those being cared for in their own homes and do not include those who reside in care and nursing homes. This allows us to closely compare data from 2022 with data from 1952.

Demographics
Though some demographic information was requested from respondents, such as their ethnic identity, gender and sexual orientation, no such data was collected about patients. Therefore, we aren't able to comment on specific patient groups by demographics.

3. Care professionals and recipients: then and now

We were interested to know who was delivering end of life care and to whom. This chapter describes the sample of respondents from the 1952 and 2022 surveys.

1952 care professionals and recipients

The 1952 survey was concerned with the care delivered by district nurses in people's homes. Nurses were invited to complete the questionnaire about their patients. The questionnaire included 50 questions covering details on patients' illnesses, living condition, nursing and welfare facilities and unmet needs. The final 1952 sample consisted of 7,050 patients with cancer, representing 179 of 193 health boards, from all four nations (England 81%; Wales 6%; Scotland 11%; Northern Ireland 2%). Nearly 70% of the sample were aged over 60 years, although there was a wide age range. Over 60% were female. Most patients were described as seriously ill, with only 12% thought to be improving. More than half (55%) were described as bed-ridden and 68% were considered to have moderate to severe suffering. As one nurse wrote:

> **"Coming into contact with a great number of cancer cases, I feel that the greatest single point that can be raised is the terrible suffering these patients go through."**
> **1952 report, page 25**

This, the nurse outlined, included mental suffering.

> **"An important factor seems to be the mental suffering often caused by the prospect of an incurable and sometimes lengthy illness."**
> **1952 report, page 25**

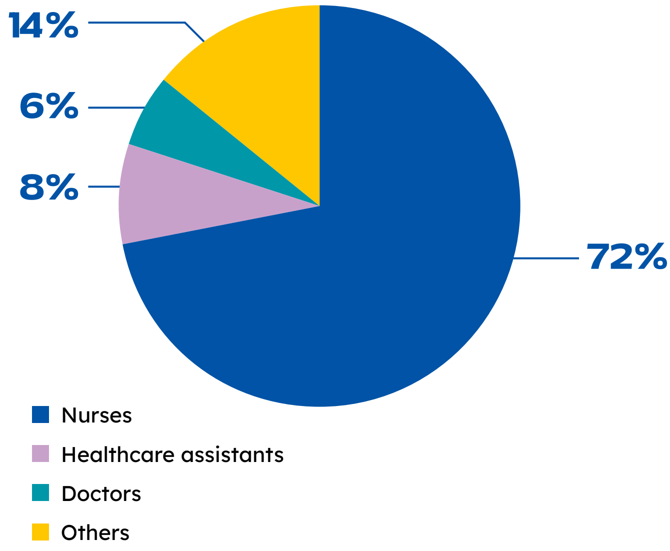
2022 care professionals

Professional characteristics of respondents

To reflect the wide range of support people receive at the end of life, we did not limit the 2022 survey to nurses. We included any professionals who care for people dying at home, both paid staff and formal volunteers. The survey received 696 responses from all four nations of the UK.

Overall, almost all the professionals were paid (96%) rather than volunteers (4%). Most respondents were nurses (72%), which was followed by healthcare assistants (8%) and doctors (6%). The remaining responses (14%) were from a range of medical and non-medical respondents such as allied health professionals, volunteers and faith community leaders. Most participants did not work exclusively with people at the end of life, though it was often a significant and valued part of their workload.

Professions of respondents



Personal characteristics of respondents in 2022

We recognise that people from different groups in society may have unique perspectives on the work they do. Because of this, we asked respondents to share some demographic information about themselves, so we could better understand who is represented in the data.

Age	Gender	Sexual orientation	Ethnic identity
Mean age was 50, with the youngest aged 21 and the oldest being 80.	91% of respondents were female, 7% were male, and 2% chose not to disclose their gender. None of the participants reported being transgender.	5% reported being bisexual, lesbian or gay.	92% of respondents self-identified as White, 2% as Asian, 2% as Black background, and 1% chose to self-describe their identity as another background. 3% did not respond.

Regions of respondents in 2022

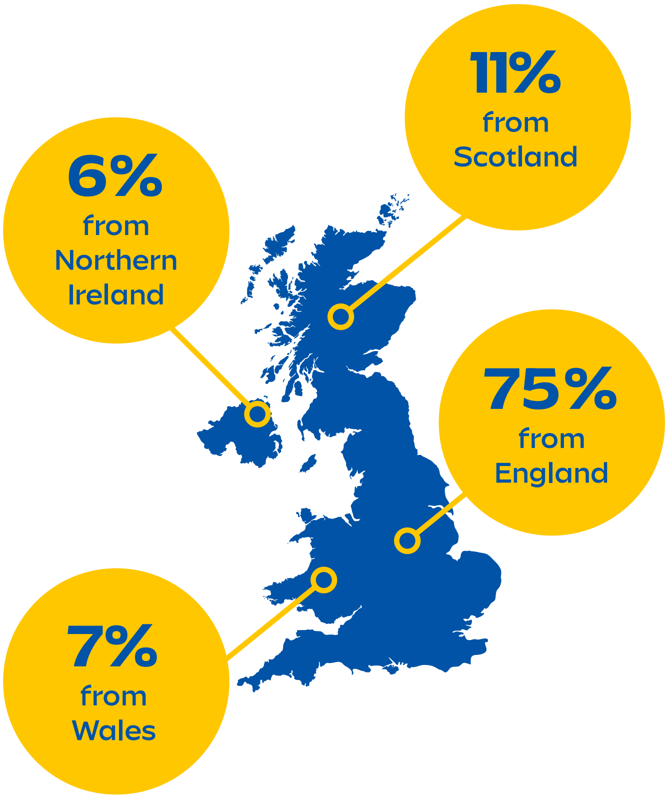
Responses came from all over the UK, as seen in Figure 2. Beyond nation, respondents were also spread across geography, with rural (19%), semi-rural (32%), suburban (21%) and urban (27%) areas all well represented. (The remaining 1% did not respond.)

Most reported their main work setting being in-home care/domiciliary (30%), community services (38%) or both (14%). The remaining participants (19%) reported their main role being in general practice, hospitals, hospices, charity services, social care or care homes, though all confirmed their role also involved some form of support for people having end of life care at home.

93%

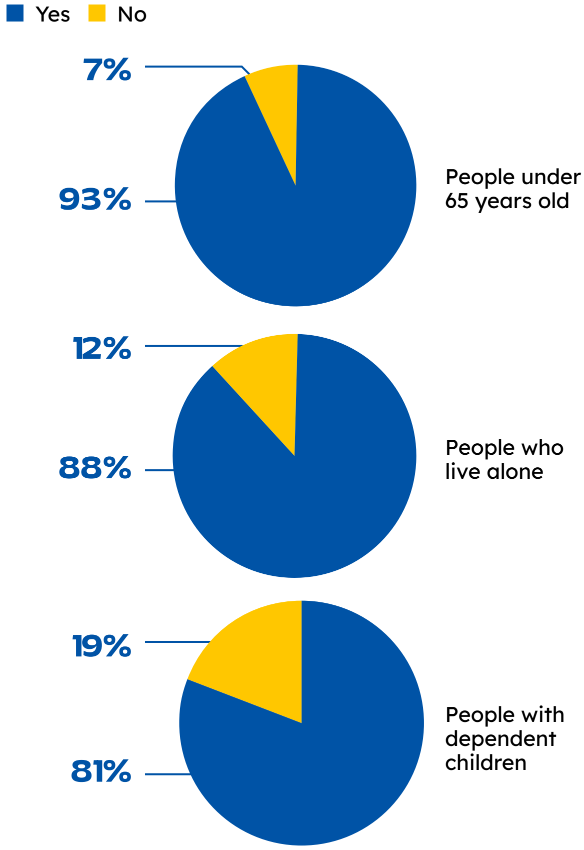
More than nine out of ten respondents in the 2022 survey provided care for people under the age of 65. In the 1952 report, nearly 70% of recipients were over the age of 60.

Figure 2. Geographic spread of 2022 respondents



1% other/did not respond

Figure 3. Proportion of 2022 respondents who regularly see the following groups

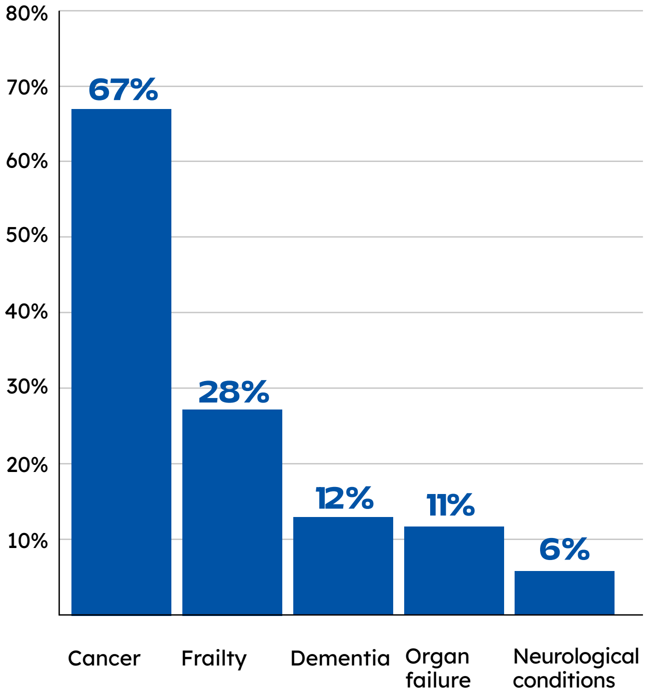


2022 care recipients

We explored how frequently the respondents had contact with people who lived alone, were under 65 years old or had dependent children, as these are all sub-groups of people known to be particularly vulnerable at the end of life. Most staff had regular contact with these groups of people, as shown in Figure 3.

We also asked how frequently respondents cared for people with specific diagnoses, and the results are shown in Figure 4.

Figure 4. Proportion of respondents who reported the following as the main diagnosis of the people they support



Understanding the range of diagnoses was important, as open-text responses showed that someone's primary diagnosis could have wider implications for the support they received, particularly when that diagnosis was for a condition other than cancer.

> **"We can access more financial support for people with cancer than those without."**
> **Nurse, head of community nursing, urban England, 2022 report**

Care professionals and recipients then and now: summary

This chapter provides evidence of the network of people involved in the provision of palliative care 70 years after the original report. Nurses and healthcare assistants, from all four nations, represented 80% of care providers. Two-thirds (67%) of respondents reported cancer as the most common diagnosis of people they saw, with frailty and dementia the second and third most common diagnoses.

Seventy years on, 93% of respondents provided care for people under the age of 65 at least some of the time. Although not a direct comparison, due to the methods of data collection, it's noteworthy that in 1952, the vast majority of patients were over 60 years of age.

4. Care delivery: then and now

We were interested in the nature of care delivery in 2022 and how this compared with that provided in 1952.

1952 care delivery

Most of the patients were cared for by their relatives and, in 1952, district nurses largely visited to relieve family caregivers, administer medications, change dressings and offer advice. In most cases, care from district nurses was delivered in the last few weeks of a person's illness.

> **"There appeared to be a tendency for the district nurse to be called in during the last weeks of illness and a number of patients died between the completion and despatch of the questionnaires."**
> **1952 report, page 24**

Paid care from health professionals was unaffordable for many people, and the NHS did not make any provision for night (out of hours) nursing in 1952. Yet just over one in five (22%) patients was reported to need night nursing. Overnight care was largely provided by relatives.

> **"It may be that actual nursing care from a trained nurse is unnecessary at night but there are all kinds of attention which the patient requires, including giving nourishment, adjusting the air-ring and pillows, helping him during hours of restlessness and giving a sedative."**
> **1952 report, page 31**

About 30% of patients were expected to need admission to hospital in the future, but respondents expressed concern that hospital beds may not be available for those who needed them most. It was noted that the challenge of providing nurses overnight was exacerbated by its unpredictable nature.

> **"Help is often needed at short notice, and for comparatively brief periods."**
> **1952 report, page 38**

The report concluded a person-centred approach was needed.

> **"The needs of those nursed at home vary widely and we have shown that, in spite of the relief work already being done, some patients still need help in obtaining the necessities of life. More assistance could be given if each case were considered on its merits."**
> **1952 report, page 42**

In response to these findings, the 1952 report recommended that there was a need for residential and convalescent homes, night nursing, casework, and more information for patients and families on their illness and what was available to help them.

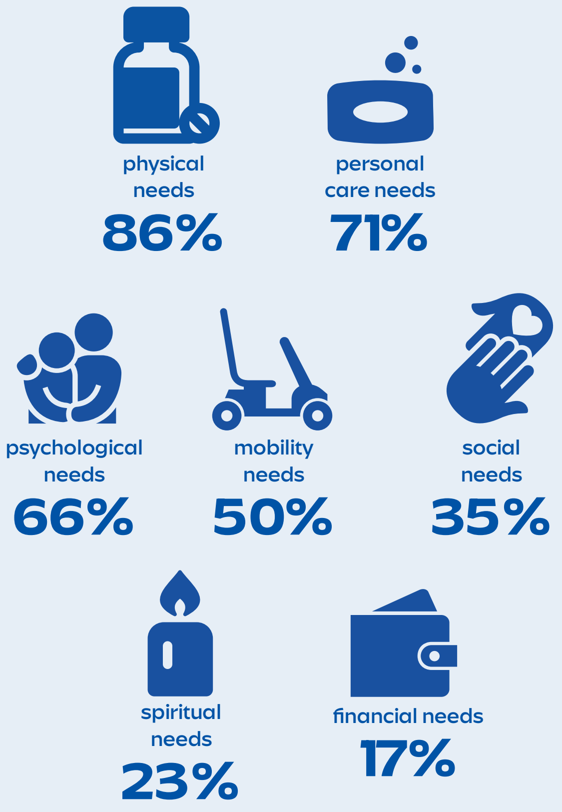
2022 care delivery

The period over which care was given for an individual patient varied widely, with respondents reporting periods ranging from a few days to more than a year. Overall, the shorter the time frame, the more likely staff were to report seeing patients that were at end of life.

We wanted to understand what needs were being met during these visits, and during remote support sessions, so we asked respondents what types of needs the people they supported had (Figure 5).

Figure 5.

Percentage of respondents who said most of their patients had the following needs:



Capacity challenges and care delivery

Other research has highlighted the challenges of providing services and staffing to meet the needs of people at the end of life[19]. Changes in multi-disciplinary palliative care delivery since the Covid-19 pandemic have particularly impacted community nursing services, providing both opportunities and challenges[20]. With this in mind, we asked staff what types of needs they do not have time to address. Close to nine out of ten respondents (86%) reported not having the time to meet a form of need applicable to their role, at least sometimes.

Capacity challenges: impact on respondents

> **“End up treating the symptom not the person.”**
> **Nurse, rural England, 2022 report**

We provided an open-ended space for respondents to explain what impact they’ve experienced from lack of time, which 59% completed. Respondents reported that lack of time made services less holistic, and this placed pressure on staff and also impacted patients and their families.

> **“Feel like I am rushing and not giving the right amount of time especially psychologically. Also, if visits come in for symptomatic patients, it puts added pressure on staff who already have unrealistic lists and we should have capacity for these priority patients.”**
> **Nurse, urban England, 2022 report**

Figure 6. Word cloud of responses around impact of lack of time

Respondents reported feeling frustrated despite prioritising the needs of people at the end of life.

> **"Within the inpatient environment in the hospice and hospital I am frustrated by the lack of time, the basic care that can be missing and the lack of "extra" care provided to really make an impact on the experience of care. Staff are tired, resources are scarce and there is greater acceptance of lower standards."**
> **Consultant doctor, rural England, 2022 report**

Respondents also reported feeling guilty, distressed and anxious about lack of time, as shown in the word cloud (Figure 6). This emotional impact affected job satisfaction, burnout and work/life balance.

> **"It affects you very badly. You go home worrying and can't sleep or switch off."**
> **Healthcare assistant, semi-rural England, 2022 report**

Several reported they had considered leaving or had left their role.

> **"I left my job as it was soul destroying not being able to provide the care that these patients and their loved ones deserved."**
> **District nurse, semi-rural England, 2022 report**

Remote/digital care delivery

Just over one-third (35%) said they offered remote support, including virtual consultation, by phone, video, text or email, which was seen as time-efficient.

> **"If they need to be seen urgently but my timetable doesn't allow it, I'll offer a virtual appointment instead so they can get the support they need quicker."**
> **Allied health professional, semi-rural Wales, 2022 report**

Remote support was also offered to those caring for the patient, for both professional care providers and family caregivers. For families or unpaid caregivers, support line calls for social support, comfort or bereavement support were mentioned.

> **"We provide psychosocial, spiritual and emotional support to those patients and their families in the community (and in day service and IPU here at the hospice) – through counselling, supportive calls, social work and spiritual care."**
> **Psychosocial counsellor, suburban England, 2022 report**

Care delivery out of hours

Most respondents worked with a patient base in need of out of hours care (defined as care outside typical business hours, such as during the evening, at night or over weekends). When respondents were asked if they felt families of people at the end of life were supported enough to know where to get help out of hours, about one in six reported that support was mostly or always insufficient. (A technical issue meant only 54% of the sample was shown and responded to this question).

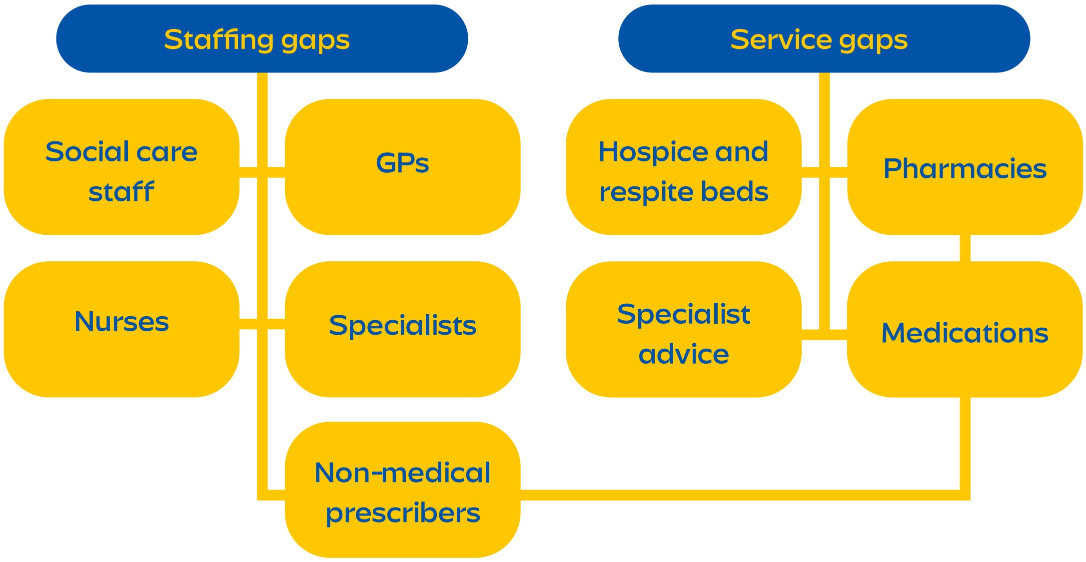
Furthermore, when given the opportunity to share open-text details in response to the question, "Have you seen any impacts on people at the end of life due to a lack of care being offered outside of normal business hours?", respondents reported numerous challenges with distressing repercussions. Responses centred around gaps in care and how these gaps impacted the people being cared for, those around them, and wider services. A map of gaps is shown in Figure 7.

Figure 7 represents the primary links between themes. Most care gaps could be attributed to lack of either staff or capacity, or of available/accessible services. These gaps were closely connected.

> **"….lack of packages of care provision. lack of increase in package of care ability. Junior staff making complex decisions out of hours when usual GP or nursing staff not on duty. No access to non-medical prescribers. Advice from specialist services nil after working hours end and weekend. Palliative and end of life patients do not stop needing specialist advice after working hours end."**
>
> **Team lead nurse, semi-rural England, 2022 report**

A lack of non-medical prescribers was reported to be linked to difficulties in accessing medications in a timely way, and an increase in non-medical prescribers was reported to be linked to reduced issues.

Figure 7. Map of staffing and service gaps



> "Lack of non-medical prescribers means that patients and/or families often have to travel to an out of hours base to access prescriptions."
> **Nurse, semi-rural Wales, 2022 report**

> "Previously it [out of hours care] was more difficult due to lack of medical staff but now we have access to non-medical prescribers."
> **District nurse, urban England, 2022 report**

These gaps impacted patients, their families and carers, and the respondents themselves.

> "Delays can be stressful for patients and their families, my aim would be for patients to receive all of the care they need as soon as possible but this cannot always be achieved out of hours due to reduced staffing and availability of care."
> **Community nurse team manager, semi-rural England, 2022 report**

Impact on unpaid caregivers:

> **"Families are having to bridge care and going into carer breakdown/crisis. This can be traumatic not only to the patient but to the family. You only get one chance of getting PEoLC right, if they have a bad experience this can lead to trauma and altered memories of their loved ones after their passing."**
>
> Community nurse, urban England, 2022 report

Impact on respondents themselves:

> **"To have a patient soiled, uncomfortable, in pain for up to 2 hours due to a skeleton night service is very distressing for not only the patient but for myself too."**
>
> Healthcare assistant, suburban England, 2022 report

Impact on patients:

> **"Having to wait for care needs to be met such as toileting/hygiene needs due to teams' clinical commitments elsewhere – undignified way to leave patients through no fault of their own, risk of breakdown in skin integrity. Time delay to attend alarming pain relieving pump for same reason above – patient left in pain, family worried. Delay on death certification due to appropriately trained staff being elsewhere in locality – massive psychological impact on distressed families."**
>
> Heart-failure specialist nurse, semi-rural England, 2022 report

Care delivery then and now: summary and recommendations

While nurses remain the primary providers of PEoLC in the community, there has been a notable shift in the range of providers within the system since 1952. Despite this, nine out of ten respondents in 2022 reported not being able to meet patient or carer needs at least some of the time. These respondents reported not having time to provide holistic care for patients and their families in the way they wanted.

Simply put, the need for holistic PEoLC is currently outstripping the capacity available to deliver it, and the effect of this is wide-reaching. In fact, the data suggests that the impacts may extend beyond end of life care, particularly for nurses who prioritise the needs of patients at end of life, ultimately impacting those with long-term conditions who are earlier in their disease trajectory. Digital and virtual care may be an avenue for more efficient triage or to provide a stopgap when services are stretched.

The findings highlight why it's critical to get PEoLC and support right for patients and families, 24 hours a day, seven days a week. Despite significant developments in the delivery of end of life care in the last 70 years, it's clear from this report that 24/7 care remains a challenge. One in six respondents reported that support out of hours was mostly or always insufficient.

Ensuring 24/7 PEoLC across the UK would also help reduce health inequalities. There is existing evidence that out of hours emergency attendances in the last year of life were higher for people living in more deprived areas across the UK[21 22]. Inequality of access to out of hours care must be viewed in the context of wider inequalities when it comes to access to EOLC.

Marie Curie is calling for every local area to provide 24/7 PEoLC through a single point of access, which offers advice, guidance and support at the end of life.

As it was in 1952, much out of hours care is still left to unpaid caregivers. And care packages to support people at home are inadequate. Timely access to medication supplies and responsive, skilled visits for symptom control are critical. There are progressive initiatives, such as increasing non-medical prescriber numbers, which have the potential to address some of these issues[23]. Marie Curie is calling for improved access to palliative medicines, better pharmacy supplies and more professionals trained to prescribe them in communities.

Currently, an estimated 90% of people who die in the UK could benefit from palliative care. If this remains constant, by 2048, we will see a 25% increase in the number of people needing care. The UK needs a health and care workforce that can respond to this increased future need. This will also demand a new funding model for PEoLC providers. For this reason, Marie Curie is calling for three key actions.

- Increased recognition of PEoLC as a core component of our health and care system; this skilled care is often provided and co-ordinated by community nursing teams.

- Parity of esteem for those working to deliver support for dying people in the public, private and charity sectors, including hospice charities.

- A funding model that reduces reliance on charitable donations, and ensures providers are paid fairly and equitably for integrated services.

5. The social condition of dying

We wanted to understand the social condition of dying at home, and how issues of poverty or financial hardship affect EOLC delivery in people's homes.

The social condition of dying at home in 1952

The 1952 report was uniquely focused on the social condition of dying. The findings from 1952 suggested that patients were suffering additional distress because of financial hardship. The oldest patients were particularly vulnerable to poverty. Despite precarious housing conditions, with patients described as living in "squalor", many were reluctant to leave their homes.

> **"In some instances, their suffering was aggravated by squalid surroundings, which they were unable to improve by reason of infirmity, and which they were often reluctant to leave."**
> **1952 report, page 15**

The findings showed that many patients experienced a lack of amenities, including heating and hot water, and one in 20 patients lacked adequate cooking facilities. Homes were described as damp, cold and poorly ventilated.

> **"The patient lived in a small cottage said to be 'partly condemned'. He slept in a tiny dark back bedroom, sometimes used for cooking, but he and his wife did not complain as the rent was low."**
> **1952 report, page 34**

There were also instances of extreme overcrowding, albeit rare. However, there were many examples of people living with extreme poverty. For example, one patient lived with dirty clothing as she had no access to laundry and went hungry as she gave food to her pets that she herself needed.

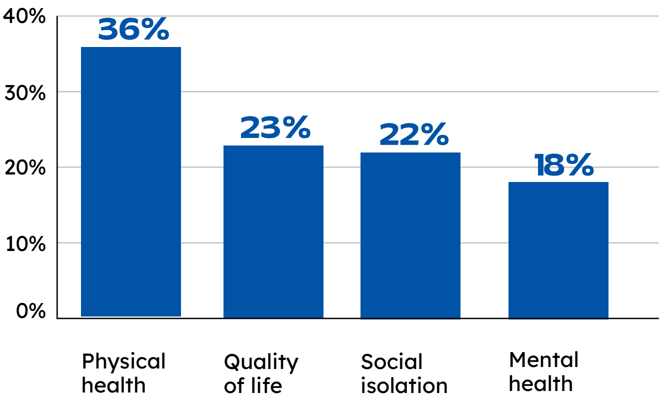
> **"Her house was dirty and she was too ill to clean it, and her clothing filthy with neglect and discharge from the ulcer. She gave food to her pets which she needed herself."**
> **1952 report, page 19**

The report also highlighted how seriously ill people appreciated "small delicacies", which were unaffordable or scarce. When asked about their needs, 48 patients had needs not listed in the questionnaire and this was usually money to buy fuel or help with laundry. Only 7% were in touch with welfare organisations, which suggests many did not know what was available to them.

End of life care for people experiencing financial hardship in 2022

Seventy years on from the 1952 report, people are still experiencing financial difficulties that significantly impact their end of life experience. In the quantitative data, a significant minority of respondents shared that at least some of the people they cared for had difficulty accessing adequate food (46%) or heating (47%). The majority of respondents shared that they regularly cared for people who had difficulty accessing appropriate housing (52%), benefits (53%), equipment (56%), medications (62%), information (63%) or transportation (68%).

Figure 8. Providers reporting negative impact of financial hardship in key areas for at least half their patients



Respondents were asked what proportion of their patients experienced financial hardship that negatively impacted their mental health, physical health, social isolation or overall quality of life. Figure 8 highlights that many respondents worked with people struggling due to financial hardship.

Over half (58%) of respondents said they had cared for people for whom a food bank would have been helpful and, shockingly, 7% said at least half of the people they care for need a food bank. Furthermore, three-quarters reported supporting people who could benefit from advice on accessing welfare support. This indicates that most PEoLC professionals working in people's homes regularly see patients who struggle to afford adequate food or need guidance about support entitlements.

We asked respondents about the challenges of providing support for those experiencing financial hardship. Most (463 people) reported issues concerned with living environment, as well as access to equipment and medication.

> **"Difficulty with maintaining comfortable environments at home. Issues with appropriate and safe nutritional intake. Even inability to access basic continence and toileting products to provide safety, comfort and dignity."**
> **Allied health professional, semi-rural England, 2022 report**

> **"The homes we provide care in can be cold, unsuitable, cluttered and unhygienic. Cold especially during the night at any time of year as people put heating off at night to save money."**
> **Community nurse, rural Scotland, 2022 report**

People at end of life experiencing financial hardship faced further challenges related to the increased cost of living at the time of the survey. These included emotional strain on patients, families and healthcare professionals; the challenge of delivering holistic EOLC; and the increased risk of social isolation, particularly in rural areas.

> **"Patients have been turning off oxygen machines as it has become expensive on electrical bills – leaving them breathless and in pain, often self-medicating with Oramorph."**
> **Community nurse, team leader role, urban England, 2022 report**

Respondents reported that patients below pension age and those with dependents were particularly vulnerable.

> **"Younger patients who were of working age and providing for their family previously, this can add an extra layer of burden and worry for them, particularly when they have children."**
> **Specialist palliative care nurse, urban England, 2022 report**

Respondents stressed the lack of access to information about financial support, social care packages and benefits advice.

> **"Not knowing what financial support or benefits are available for patients. At the hospice we have a benefits advisor who liaises directly with the patients."**
> **GP, semi-rural England, 2022 report**

Respondents noted financial hardship potentially leading to emotional strain for patients and families.

> **"The overwhelming worry of poverty/financial burden can prevent the latter days from being calm and relaxed; patients often worry about financial implications for those they leave behind. They worry about debts and what happens with them."**
> **Palliative care specialist nurse, urban England, 2022 report**

Even when support and benefits were available, overly complex bureaucratic processes created unnecessary barriers for patients and families. Over half (56%) of respondents said they had patients with difficulties accessing benefits, but lacked sufficient time to address this.

> **"No flexibility within the benefits system to speed things up… Bureaucratic system requiring people to answer difficult questions at difficult times, with an over emphasis on online work (long waits on telephone to speak with an… advisor)."**
> **Social worker, suburban England, 2022 report**

Patients without access to public funds, or who are ineligible to register with a GP due to immigration status, may be particularly vulnerable.

> **"It can be extremely challenging for patients who are not eligible to register with a GP due to immigration status to overcome these barriers in order to access financial support, palliative hospital treatment and community services."**
> **Specialist palliative care nurse, urban England, 2022 report**

Overall, respondents noted that the impact of financial hardship could lead to poor quality of life and contribute to inequalities between patients with access to private care and those without.

> **"People have less choice if… financially compromised which leads to more disadvantaged dying… [For families]… negative experience of death… can have lifelong impact."**
> **Specialist nurse for dementia patients, urban England, 2022 report**

The social condition of dying: summary and recommendations

It's deeply concerning that despite the UK being considerably wealthier than it was 70 years ago, financial hardship remains widespread among people who are at the end of life. Too many people at end of life still live in unsuitable housing and are still unable to afford basic amenities, food and heating. It's hard not to be shocked that almost 60% of respondents said they had cared for people for whom a food bank would have been helpful.

In 2019, 90,000 people died in poverty[24]. And the data in this report supports our belief that the current figure is likely higher. It's vital that we act to ensure that nobody dies in poverty.

Despite the increased availability of financial support compared to 1952, it too often fails to reach those who need it most. Over half of the respondents in the recent survey cared for patients who had difficulty accessing benefits, often the result of lengthy, overly complicated and excessively bureaucratic systems. Yet alarmingly, most respondents did not have sufficient time to address financial concerns, despite recognising it as a critical aspect of their job.

Marie Curie is calling for the Department of Work and Pensions (and relevant departments in the devolved nations), to work with NHS and other providers to ensure they are signposting people at end of life to financial support entitlements; and for more advocacy officers to help people at the end of life understand their rights and entitlements, and to help with claiming benefits.

While in 1952, older people were at highest risk of poverty, we know that now it is people of working age with young families who are particularly vulnerable at end of life[24]. Marie Curie is calling for entitlement to claim State Pension and other pension age benefits for working age people at the end of life, to ensure they aren't pushed into poverty simply for dying too young. Marie Curie research further confirms the well-documented intersection between racialisation and poverty; two in five working age people from minoritised ethnic groups die below the poverty line, and 27% of pensioners from a minoritised ethnic group are dying in poverty, double the figure for white pensioners.

A further, related consideration is unsettled immigration status or the no recourse to public funds (NRPF) condition, which compounds the risk of poverty at the end of life. Currently, people with NRPF can access palliative care services provided by a registered palliative care charity or community interest company, such as a hospice. However, given the well-documented inequities that exist in PEoLC services for minoritised ethnic groups and those living in poverty, especially given their increased likelihood of using emergency services, we're concerned that significant gaps in care persist. Furthermore, bereaved people and unpaid carers with NRPF will face further challenges in accessing support.

Marie Curie supports calls for the Home Office to scrap the NRPF condition imposed on migrants with limited or no leave to remain, to ensure equitable access to PEoLC, and support for unpaid carers. We're also calling for each UK nation to have a cross-government strategy to address health inequalities throughout the life course, including at the end of life.

6. Community, connection and caregiving at end of life

We wanted to understand what support is available within communities – including unpaid caregiving – from family and friends at end of life, in different geographies and how this has changed over 70 years.

Geography and community connection in 1952

After the second world war and the introduction of the NHS Act in 1948, there were developments in statutory and voluntary care. For example, home help services were available to about 84% of the sample, although only used by a minority. Initiatives such as Meals on Wheels were important in terms of both providing nutritious food and connecting patients to the outside world; they were considered invaluable to those who lived alone.

One of the main findings from the 1952 survey was that different problems were identified for people living in towns (69%) compared with villages and the countryside (31%). Differences were noted in the type of housing, the available amenities and community support. For example, the report described that "neighbourly kindness" was more readily available to those living in the country, but the provision of initiatives such as home help and Meals on Wheels was challenging.

> **"In village and country life there is often a livelier sense of community than in a large town, and neighbourly help is often easier to obtain. On the other hand social services such as home help or mobile meals are not easy to take to a rural population, especially where transport facilities are inadequate."**
> **1952 report, page 27**

As a result of this, there were some patients in rural communities who received many more district nurse visits than typical, with some receiving hundreds of visits over the period of a long illness.

> **"In rural communities there were a number of patients not actually needing attention who were visited for observation and advice about their illness."**
> **1952 report, page 35**

In the 1952 report, unmet social needs and the importance of community-based recreational activities to provide social connection were documented. The issue of loneliness was described as particularly prevalent for older people, and was exacerbated by their illness.

> **"It was among the elderly that some of the gravest social problems were found. Some patients depended on an equally aged wife or husband, others had outlived all their friends and relatives and suffered acutely from neglect and loneliness."**
> **1952 report, page 15**

> **"A lot of elderly people longed for congenial company and for occasional conversation."**
> **1952 report, page 40**

Geography and community connection in 2022

Respondents in our 2022 survey worked across geographies with over 50% in rural or semi-rural locations. There were particular challenges for people living rurally. For example, based on the open-text answers, support for patients and families in rural areas was often found to be insufficient to enable them to stay at home at the end of life and avoid unwanted admissions to hospitals and hospices. Results from the quantitative data were significant. Those in rural areas had the lowest levels of support to avoid unwanted admission, yet there were fewer options for where they could go if needed, meaning they had to travel significant distances.

> **"Patients are dying at home, and when families reach crisis point they can't be admitted to palliative beds locally but again have to be transferred... It is actually shocking and sad that these patients and families in our region are being let down badly. The 24-hour service we provide is good and needed, but the health board needs to employ more staff to open the hospital and provide 24-hour care."**
>
> **Community nurse, rural Scotland, 2022 report**

Social isolation and loneliness

There are similarities between the impact of geographic isolation and of social isolation from living alone. Of the respondents to the 2022 survey, 88% provided care for people who lived alone. Those who lived alone were reported to have less support to die in the place they wished.

> **“Without unpaid carers it is extremely difficult to support patients undergoing EOLC, to remain at home. Social services in this area are limited. Within [Central Scotland health board area], it is a postcode lottery for service provision. Different hospices also provide different services to community-based patients.”**
>
> **Advanced nurse practitioner, urban Scotland, 2022 report**

97%

of 2022 respondents reported seeing people who experience loneliness.

This lack of support is heightened outside normal business hours.

> **“End of life patients, particularly those who live alone, are sometimes frightened during the evening and night time. Usually there is just an out of hours skeleton staff who have a large geographical area to cover. This not only impacts on the patients but family carers and the staff.”**
>
> **Community nurse, rural England, 2022 report**

We explored whether this connection held up in the quantitative data and the results were significant. Staff who reported seeing more patients who lived alone also reported seeing more patients who were not able to have their wishes met regarding their place of death.

A closer look

Respondents in urban areas and those who had very few patients who lived alone were less likely to report that their patients had difficulties with accessing out of hours care. This supports the qualitative findings that patients who lived in rural areas, or who lived alone, had less support for care out of hours.

The majority of respondents (88%) felt that helping to alleviate social isolation was within the remit of their role. But 79% reported not having enough time to support this need, at least sometimes, demonstrating that, while the need has been identified, respondents are often not equipped to address these needs themselves. Social isolation was aggravated by issues of financial hardship, with 87% of respondents sharing that they had at least some patients who faced financial hardship, which made them more socially isolated.

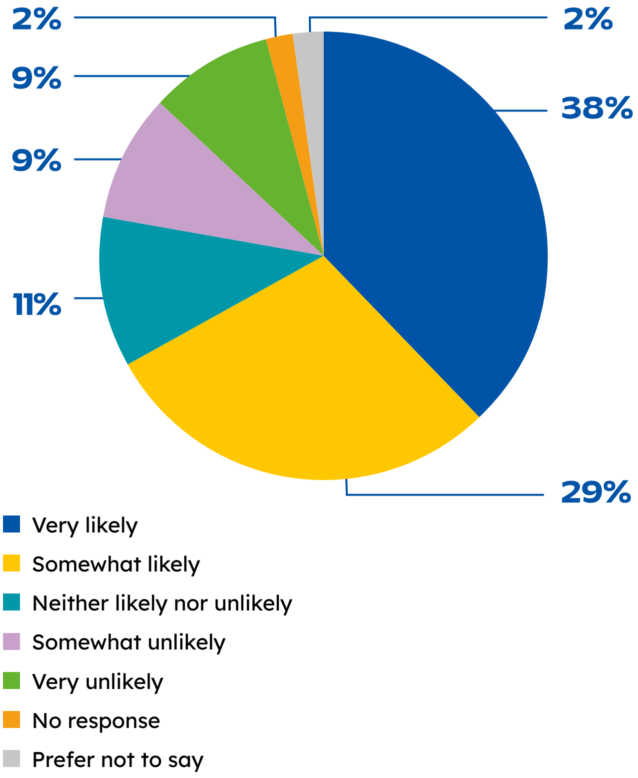
> **“Rising fuel costs have affected patients’ ability to socialize which as a result caused social isolation. Social isolation has been reported to be specifically prevalent in rural areas.”**
> **Psychosocial counsellor, suburban England, 2022 report**

Seventy years on, it’s evident that loneliness remains an issue for people at the end of life. Only 3% of respondents said none of the people they cared for were lonely. And nearly one in 10 (9%) said most unpaid carers they saw experienced loneliness.

Community support

Staff were asked how likely they were to refer the people they supported to community support services. Overall, about two-thirds (67%) reported they were either very or somewhat likely to refer to community support services. However, 18% reported they were very or somewhat unlikely to make such referrals. This is striking when compared to the rates of reported need: only 1% of respondents said none of their patients had needs that could be met by a community support organisation. Full details are shown in Figure 9.

Figure 9. Likelihood of respondents referring patients to community support



Among the 99% of respondents reporting some patients needing community support, benefits advice was seen as helpful to the the largest proportion of patients. This was closely followed by community groups, mental health groups, housing advice, food banks and, lastly, immigration advice. Over the past 70 years, the landscape of community support has expanded significantly, with many organisations now providing these services compared to the situation in 1952. However, despite this growth, challenges persist in terms of referral and uptake.

Respondents were invited to describe their relationships with local community support organisations in an open-text space. Of the 483 who responded, approximately half described the relationship as good and about one-fifth as limited or inadequate.

As an example of a positive relationship with community support groups, one respondent said:

> **"I use the wider community as an intrinsic part of the support system for individuals. I believe that we should think of ourselves as an alliance of support across a community. The important thing is to have someone co-ordinating the care chain."**
> **Specialist palliative nurse, rural England, 2022 report**

However, it was evident from the data that knowledge was key to being able to use this "alliance of support". Respondents acknowledged the importance of local and up-to-date knowledge of community support organisations so they could readily signpost patients and families. Having local hubs or a local forum to keep up to date and facilitate referrals was described as potentially helpful.

> **"I wish there were local Hubs that kept up to date information that referrals could go into as it's impossible to know what reputable organisations exist and what they provide."**
> **Nurse, semi-rural England, 2022 report**

Respondents acknowledged that often they lacked the time to familiarise themselves with what was available locally, to build relationships or to make the necessary referrals – often another lengthy process.

> **"I am probably not aware of all groups that are available as don't have time to actively find out about organisations."**
> **Community nurse, suburban England, 2022 report**

Unpaid caregiving from family and friends: 1952

In 1952, many patients were reported to rely entirely on their friends, family or neighbours for support, many of whom were in old age or ill themselves. As one respondent in 1952 described:

> **[The patient was] "totally blind and entirely dependent on kind neighbours. Her doctor was unable to secure a hospital bed, although she was critically ill".**
> **1952 report, page 15**

The caring roles taken on in 1952 were substantial. Caring regularly took place for long periods and overnight. The report suggested that the provision of residential homes could potentially alleviate some of this reliance on family and friend caregivers.

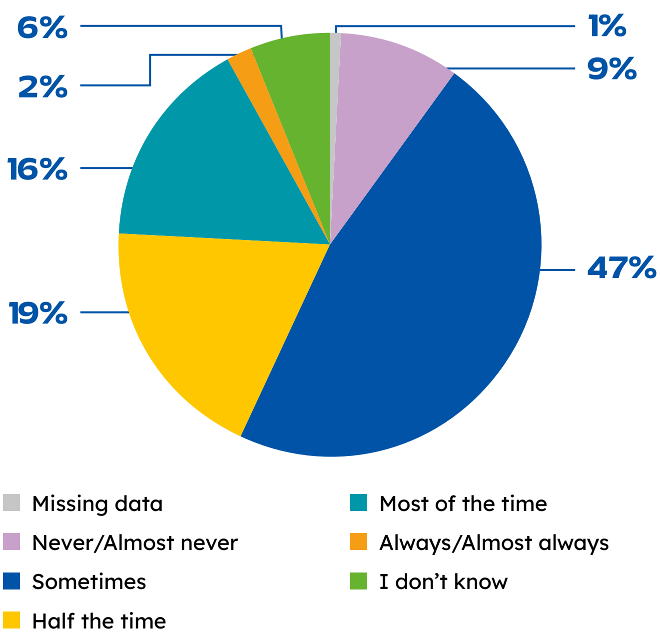
The long hours of caring within families was found to have a profound effect on wage earners, as many had to give up work. Families then incurred financial problems as a result.

Unpaid caregiving from family and friends: 2022

Although there's greater provision of care in the current NHS than in 1952, unpaid caregivers at home still undertake substantial caring roles at end of life. Nearly all respondents (97%) reported that the people they supported had unpaid care from family, friends or neighbours.

When asked how well supported these unpaid carers were, either through formal support services or informal support from friends or family members, many said unpaid carers were without support, with 56% of respondents reporting that unpaid caregivers either never received support, or only sometimes received support. Figure 10 shows that only 2% of respondents reported that the unpaid caregivers they saw were consistently supported.

Figure 10. How often are unpaid carers supported?



We asked respondents how caregivers could be better supported. Answers given included financial support; counselling; social carers/paid care; carer assessment (local authority); recognition/appreciation of their role; training to undertake the role; advice out of hours; hospice support line; bereavement support; employment support; and respite.

Respondents were asked how support for unpaid caregivers could be improved. Time to provide holistic support was reported to be critical, as was the need for simple systems to expedite timely support when the caregivers needed it.

Identifying someone as a carer was the vital first step, but could be challenging; many people don't consider themselves to be carers and did not want to be labelled as such.

> **"A stumbling block I have found over the past 12+ years is the non-identification, particularly among spouses, of being a carer – 'he/she's my husband/wife - it's what you do'. This can stop people reaching out or responding to those supporting carers."**
> **Psychosocial counsellor, suburban England, 2022 report**

Being identified early and involved in care planning was a facilitator to good carer support. Preparedness for the caring role was key and included access to relevant information and vital equipment at the right time, understanding "what lies ahead" and knowing who to contact in a crisis.

> **"Clarity around support (financial and practical), reduced barriers to accessing help, not having to fight for things, improved communication, honesty from professionals on reality of provision available and how to access it."**
> **Trainee doctor, urban Scotland, 2022 report**

Throughout the support process, clear communication was important. Respondents highlighted the importance of listening to carers and making "things as uncomplicated as possible".

> **"If we don't do this, multiple referrals to different professionals and teams results. This unintentionally increases burden on the carer – coordinating numerous appointments, phone calls, retelling what's happening, managing the logistics. All this is in addition to the sadness and grief. We need to make things as uncomplicated as possible."**
> **Consultant doctor, suburban England, 2022 report**

Respondents also noted the importance of having protections in place to ensure carers didn't lose employment while taking time to care for their loved one.

> **"Often the dying process is long and particularly in younger patients, can be unpredictable. I feel that often spouses and adult children find it difficult to access support due to the unpredictability of the disease progression. Often they continue to have to work or access sick leave."**
> **District nurse apprenticeship student, urban England, 2022 report**

Community, connection and caregiving at end of life: summary and recommendations

Staggeringly, 97% of respondents cared for people experiencing loneliness at the end of life. This is despite the fact that virtually all (99%) felt need could be met in their communities, including through benefits and housing advice and support to improve mental health and wellbeing.

In too many cases, despite recognising the potential "alliance of support" within communities, practitioners reported not having the knowledge or relationships to connect people with these services. Social support and connection to community remain vitally important for people at end of life. We need innovative solutions with local relevance to enable communities to provide this much-needed support.

As was the case in 1952, different issues were noted between urban and rural areas. It's concerning that people experiencing isolation, whether geographical or social, still don't have equity of end of life experience. Marie Curie is calling for innovative solutions to eliminate the current postcode lottery in access to palliative care and to address inequity through personalised EOLC and support plans for every individual reaching the end of their life. However, the experiences and provision of support for people living in more geographically isolated circumstances – such as remotely or rurally – and of those living alone warrant more research.

It's important to note that many marginalised groups face additional barriers in accessing PEoLC, including people living in poverty; living alone; with dementia; with learning disabilities; homeless; poorly housed; in prison; from racialised, minoritised ethnic groups; or from LGBTQ+ groups. For many, these characteristics intersect with socioeconomic deprivation[25]. For this reason, a cross-government strategy is needed, in each nation, to address health inequalities.

Unpaid PEoLC from family and friends is still widespread, particularly out of hours. So, it's extremely worrying that more than half (56%) of service providers reported that unpaid carers aren't getting the support they need to care for others or themselves. We know from previous research that these caring roles can profoundly impact carers' health and wellbeing, whether physically, psychologically or financially[26 27].

To address this, Marie Curie is calling for increased support for carers of people at the end of life, through better identification, needs assessment, and financial and bereavement support. This should be enacted through personal support plans for family and carers, which include bereavement and mental health support.

7. Addressing the gaps in end of life care – 70 years on

We conducted this research 70 years on from the 1952 study and, although much has changed, many issues persist. Now as then, we found too many people dying at home without the care and support they critically need – particularly outside normal business hours. Many people are still facing severe poverty and deep social isolation at end of life.

Chapters 3 and 4 of this report highlight that, despite the wider range of end of life care providers compared with 1952, nine out of ten respondents in 2022 couldn't consistently meet patient and unpaid caregiver needs. Simply, the demand for holistic, 24/7 end of life care is surpassing the current capacity available to deliver it. One in six respondents noted that out of hours support was often insufficient, placing a significant burden on unpaid caregivers – mirroring the situation observed in 1952, when formal social care packages were largely unaffordable. Furthermore, in 2022, 56% of service providers reported that unpaid caregivers lack the support they require to care for others and themselves.

At the time of the 1952 survey the second world war had quite recently ended, rationing was still in place and the UK was experiencing the effects of the recent flu epidemic. Despite some of this shared context, namely the Covid-19 pandemic and the 2022/2023 cost-of-living crisis, chapter 5 confirms the sobering situation that, despite 70 years of increasing wealth having transformed the UK, we've still drawn the same conclusion as the 1952 report: that "considerable hardship exists" at end of life (page 41 of the original report).

It's impossible not to be shocked that in 21st century Britain, over half of palliative care providers said they care for people for whom a food bank would be useful. Similarly, it was noted in 1952 that many patients were "unaware that they may be eligible for much needed financial help" (page 41). That these issues remain unchanged is shocking. In 2023, it's unacceptable that people at the end of their lives are facing the stark impact of poverty.

As we saw in chapter 6, a staggering 97% of respondents noted loneliness as a prevalent issue among those receiving care at home, and yet virtually all respondents believed that community-based solutions could effectively meet the needs of those they cared for. However, disparities persist, with many people experiencing isolation, whether geographical or social, and still not achieving equity in their end of life experiences. Cumulatively, these findings emphasise the need to address issues of equitable access to PEoLC and support within local communities.

It's clear from this report that significant systemic changes are needed to address the complex and persistent challenges that continue to impact end of life care 70 years on.

Next steps: addressing the gaps 70 years on and in the future

Even after the birth of the hospice movement, and seven decades of development in the delivery of palliative care, too many people are still not receiving the support they need at the end of life. This research must be a catalyst for change.

Addressing the persistent challenges requires co-designed services tailored to meet local need, evidence-informed innovative solutions and a committed focus on equitable, holistic support for people at the end of life, and those close to them.

Research and influencing are at the heart of Marie Curie's activity and have been since its inception. In partnership with the QNI, we're ideally placed to consider what the findings in this report mean for the end of life system, now and in the future. As the UK's leading end of life care charity, Marie Curie is recommending change in four key areas.

- Too many people are dying at home without the care and support they critically need – particularly out of hours. **A new funding solution for hospices and PEoLC is required**, to end the postcode lottery in access and recognise PEoLC as a core component of our health and care system.

- The demand for holistic, 24/7 end of life care surpasses current delivery capacity. **A national PEoLC strategy, supported by a delivery plan for local services, is required** in every nation. This must include 24/7 access to PEoLC, through a single point of access in every local area; and improved access to medicines through more pharmacies stocking palliative medicines and more professionals trained to prescribe them in communities.

- It's essential we tackle the profound inequalities in end of life experience, through a cross-government strategy in every nation – to **end poverty at end of life**, and address health inequalities throughout the life course. This should ensure terminally ill people of working age can claim State Pension and other pension age benefits; and protect everyone with a terminal illness from high energy costs, through targeted support, a social tariff on energy prices and improved government support for the cost of running essential medical devices at home.

- Over half of palliative care professionals in 2022 reported that unpaid caregivers lack the support they require to care for others and themselves. It's vital to **improve support for families and carers of people with a terminal illness** through better identification, needs assessment, and better financial and bereavement support. Each nation of the UK must also have a clear cross-cutting plan for bereavement.

How we treat people who are dying is a key marker of a civilised society. In 1952, Marie Curie and the QNI made the case that we must respond to this responsibility through the development of the hospice sector. It's our shared ambition that this sobering report should serve as a catalyst for much-needed change. In the face of these deep-seated challenges, it's imperative that we reshape the end of life system and re-evaluate the resources needed to deliver care, so that everyone at end of life and those close to them has the best possible experience.

Figure 11. Recommendations for change

A new funding solution for hospices and palliative and end of life care – to end the postcode lottery in access, reduce reliance on charitable donations, and ensure services are fit for the future.

A national palliative and end of life care strategy, supported by a delivery plan, in every nation. This must include 24/7 access to care, through a single point of access in every local area, as well as improved access to medicines.

An end to poverty among people at the end of life – including by ensuring that those of working age can claim their State Pension and other pension age benefits; and protecting everyone living with a terminal illness from high energy costs through targeted support.

A new deal for families and carers of people living with a terminal illness – including better identification and needs assessments for carers, and improvements in financial and bereavement support.

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Appendix: survey questions

This appendix shows a copy of the questionnaire given to respondents to the 2022 survey.

Background:

In 1952, the Joint National Cancer Survey Committee of the Marie Curie Memorial Fund and Queen's Institute of District Nursing produced a seminal report that highlighted areas of profound need in end of life care. This report resulted in Marie Curie opening hospices and providing nurses who go into people's homes and provide care overnight.

Over the past 70 years, those services have helped many people. However, gaps still remain and Marie Curie and the Queen's Nursing Institute are again partnering to survey what has changed since 1952 and improve support for people at end of life, with any diagnoses, in 2022.

We intend to publish our results on our website, and may also submit to academic journals or allow approved secondary analysis. No individually identifying information will ever be published in any format at any time. This survey should take 15-20 minutes to complete, depending on the level of detail you would like to provide. Participating is strictly voluntary.

The decision about whether to participate in the survey is entirely up to you. If you do decide to start the survey, you are free to skip any questions you do not want to answer or stop participating entirely at any time. You will never be asked to provide a reason for declining to answer any/all questions.

Finally, This survey is being sent to a broad group of people and some questions may not apply to your role, or you may not know the answer to some questions. Where applicable, we have inserted "NA" and "I don't know" answer options for you to use when needed.

Survey questions:	Responses:
What term best identifies your profession?	Registered nurse (Band 5, 6, 7, 8 and job title) Healthcare assistant Doctor (GP, Consultant, Specialist, Trainee) Social care provider/paid carer Allied Health Professional Social worker End of life doula Advice worker/advocate Community worker Volunteer Faith community leader Other (space to specify)
What best describes how you work in end of life care and support?	Full time paid employment Part time paid employment Full time volunteer work Part time volunteer work Other
How much of the time in your role is spent providing support for people at the end of life?	All/almost all Most About half Some Very little
Years of experience	Short text answer
What best describes the main settings in which you work? (Tick all that apply)	Primary care/General Practice Hospital Hospice Third sector/Charity Community services Social care Care/Nursing Home Other

Survey questions:	**Responses:**
How many of the people for whom you provide end of life care… 1. Live alone? 2. Are under 65 years of age? 3. Have dependent children? 4. Have an unpaid caregiver?	None/almost none Some About half Most All/almost all I don't know
How much time do you typically spend with a person at the end of their life?	Less than an hour 1-5 hours 5-10 hours 10-20 hours 20-50 hours 50+ hours
In which nations do you work? (Tick all that apply)	Scotland England Northern Ireland Wales Other
Which of the following best describes the geography in which you work? (Please check all that apply)	Rural Semi-rural Urban Suburban
Type of care provided - These questions will help us to better understand the care and support you provide.	
How often do you get to spend the following amounts of time with people who are at the end of life? 1. 7 days or less 2. 7-14 days 3. 14-31 days 4. 1-6 months 5. 6-12 months 6. 12 months or more	Never/almost never Sometimes About half the time Most of the time Always/almost always NA
How many home visits do you typically have with someone while supporting them at the end of life?	Short answer
How long, in minutes or hours, is a typical visit you have with someone at the end of life? (Please list the number and specify if it represents minute or hours, such as "15 minutes" or "3 hours").	Short answer
How many of the people for whom you provide end of life care… 1. Regularly visit a hospice? 2. Regularly attend hospital?	None/almost none Some About half Most All/almost all I don't know
Do you provide any remote consultations or other digital support to people at home who are at the end of life?	Yes (please expand) No
How many of the people you provide care for have a main diagnosis of… 1. Cancer 2. Organ failure 3. Frailty 4. Neurological condition 5. Dementia	None/almost none Some About half Most All/almost all I don't know

Survey questions:	**Responses:**
End of life care needs and capacity care and support – These questions will help us understand what care and support is being delivered in people's homes at the end of life. We also want to understand obstacles you may face in providing care.	
How many of the people you provide end of life care for require support with: 1. Physical needs (pain, nausea/vomiting, fatigue, breathlessness, etc). 2. Financial needs 3. Personal care 4. Mobility needs 5. Psychological needs 6. Social isolation 7. Spiritual needs	None/almost none Some About half Most All/almost all I don't know
How often do you feel you don't have time to appropriately provide support for the following areas? If a type of support does not apply to your role, please select NA 1. Physical needs (pain, nausea/vomiting, fatigue, breathlessness etc). 2. Financial needs 3. Personal care 4. Mobility needs 5. Psychological needs 6. Social isolation 7. Spiritual needs	Never/almost never Sometimes About half the time Most of the time Always/almost always NA
If lack of time has impacted the care you're able to provide, how has this professionally or personally affected you?	Open ended
How well would you say that care and support is provided for the following needs for families of people at end of life? 1. Information about the cared-for person's illness 2. Where to get help out of hours 3. Help with meeting physical needs of the cared-for person (medication, personal care, equipment) 4. Help with symptoms such as pain or breathlessness 5. Financial, welfare support 6. Looking after their own physical/psychological and spiritual wellbeing 7. Social isolation 8. Knowing how to get a break from caring 9. Accessing bereavement care	Almost/never sufficient support Insufficient support most of the time Sufficient support about half the time Sufficient support most of the time Almost always sufficient support NA
How many of the people you support at end of life need extra care out of hours?	None/almost none Some About half Most All/almost all I don't know
What impact can a lack of out of hours care have on people at the end of life?	Open ended
In your experience, how sufficient is the support available at end of life to prevent unwanted admissions to: 1. Hospital 2. Hospice	Never/almost never sufficient Sometimes sufficient Sufficient about half of the time Sufficient most of the time Always/almost always sufficient
How often do you have conversations about place of death or other end of life preferences with the people you support at end of life?	Never/almost never Sometimes About half the time Most of the time Always/almost always

Survey questions:	**Responses:**
How often do you feel the wishes of people at the end of life are met in regards to: 1. Preferred place of death 2. Treatment desired 3. Treatment not desired 4. Spiritual or religious beliefs 5. Appointing someone to make decisions on their behalf 6. What is done with their body after death	Never/almost never Sometimes About half the time Most of the time Always/almost always I don't know
Are there any end of life wishes you see that are regularly left unfulfilled, undiscussed or unexplored?	Open ended
Social conditions of dying in 2022 – The following questions are about how living with financial hardship impacts people at the end of their lives.	
How many of people at end of life do you see who have difficulties accessing appropriate: 1. Heat 2. Food 3. Transportation 4. Housing 5. Equipment 6. Benefits 7. Access to information 8. Medications/prescriptions	None/almost none Some About half Most All/almost all I don't know
In your experience, how many of people you support have financial hardships that negatively impact: 1. Mental health/wellbeing 2. Physical health/wellbeing 3. Social isolation 4. Quality of life	None/almost none Some About half Most All/almost all I don't know
In your experience, what are the challenges of providing support for people at the end of life who are also experiencing financial hardship?	Open ended
In your experience, are there any tools or resources you've found useful for people experiencing financial hardship at the end of life?	Open ended
Relationships and communities – The following questions are about individuals and community groups that may provide care and support for people at the end of their lives. Your answers will help us to understand what care is well-supported, where there are gaps, and how this impacts the care and support you provide.	
How many people who you provide care or support for receive unpaid care from any source (family, friends, neighbours, etc)?	None/almost none Some About half Most All/almost all I don't know
What proportion of people you support receive unpaid care from: 1. A partner or spouse 2. An adult child 3. A child under the age of 18 4. A friend or neighbour	None/almost none Some About half Most All/almost all I don't know
In your experience, how often are unpaid caregivers of people with a terminal illness well-supported?	Never/almost never Sometimes About half the time Most of the time Always/almost always I don't know

Survey questions:	**Responses:**
How could caregivers be better supported?	Open ended
Do you feel that you are doing tasks in people's homes that are not in your job description?	Never/almost never Sometimes About half the time Most of the time Always/almost always I don't know Prefer not to say
If yes, can you provide details and explain if and how it impacts your ability to provide your usual care?	Open ended
Of the **people at the end of life** for whom you care, how many do you believe are experiencing loneliness?	None/almost none Some About half Most All/almost all I don't know
Of the **unpaid carers** (such as family or friends) who also care for the people for whom you provide end of life are, how many do you believe are experiencing loneliness?	None/almost none Some About half Most All/almost all I don't know
How many of the people for whom you provide EOLC have unmet needs which could be met by community support organisations? 1. Food banks 2. Community groups 3. Mental health groups 4. Immigration advice 5. Housing advice 6. Benefits advice 7. Debt support (e.g. food banks, community groups, mental health groups) 8. Faith groups 9. Other (please specify)	None/almost none Some About half Most All/almost all I don't know
How likely are you to signpost the people you see to a community support organisation such as those above?	Very unlikely Somewhat unlikely Neither likely nor unlikely Somewhat likely Very likely
How would you describe your relationship with local community support organisations?	Open-ended
Demographics – Thank you for taking the time to respond to this survey. The questions in this final section will help us understand who is represented in our sample. Per your preferences, you can select "prefer not to say" or skip questions.	
Age	
Gender	
Ethnicity	
UK region	

More information

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The Queen's Nursing Institute (QNI) is the independent voice of community nurses, and those working in social care and primary care. We promote excellent nursing care for people of all ages, where and when they need it, provided by nurses and their teams with specific skills and knowledge. We are dedicated to building healthier communities and improving the physical and mental health of everyone in society.

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Marie Curie is the UK's leading end of life charity. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system. Whatever the illness, wherever you are, we're with you to the end.

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