



Making the case for free social care at the end of life

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1 Introduction

Macmillan Cancer Support strongly believes that people with cancer who are in the final weeks of life should have the choice to die at home, surrounded by their friends and family.

We know that access to social care services, as part of a package of end-of-life care, can help people nearing the end of life be cared for and die in their own home, if this is what they want. However, currently, the majority of cancer patients continue to die in expensive hospital beds, partly because they can't access the social care support they need.

This is why we, along with our charity partners – Help the Hospices, Marie Curie Cancer Care, Motor Neurone Disease Association, National Council for Palliative Care and Sue Ryder – want social care to be free for everyone who is at the end of life.

New research from Macmillan, compiled for the first time in this report, reveals policy makers and NHS staff who directly care for patients support the implementation of free social care for people at the end of life, so they can receive the support they need to die at home.

'The idea of free social care at the end of life is irrefutable. I don't think any of us would argue about it, and it is reasonably clear it wouldn't end up costing us more.'¹

Dame Barbara Monroe, Chief Executive, St Christopher's Hospice

Many MPs, health and social care commissioners and healthcare professionals also agree with Macmillan that this is the right thing to do. What's more, evidence suggests that the policy could save the NHS money by reducing costly and unnecessary admissions to, and lengthy stays in, hospital.

Macmillan is pleased the Government recognised 'much merit' in the policy of free social care at the end of life in the Care and Support White Paper (2012), and committed extra funds to assess this. The Joint Committee on the Draft Care and Support Bill also reiterated the importance of social care at the end of life in March 2013. In their report, which was produced following full scrutiny of the Draft Bill, they agreed with Macmillan's argument that free social care at the end of life has merit and should be introduced 'at the earliest opportunity'.²

We believe our new research adds further weight to our call for free social care at the end of life to be implemented in the lifetime of this parliament.

Our research

Over the past year, Macmillan has commissioned a number of pieces of research around free social care at the end of life. These are:

- a poll of healthcare professionals³
- a survey of MPs⁴
- a roundtable with leading experts in health and social care⁵
- in-depth phone interviews with 20 health and social care commissioners.⁶

This research demonstrated a broad base of support for the principle of providing free social care at the end of life. The case we have put together from our research, when analysed alongside studies from the National Audit Office, the National End of Life Care Programme, the Palliative Care Funding Review (PCFR) and others, adds to a growing body of evidence showing a strong moral and economic case for introducing the policy.

2 Delivering better end-of-life care

We only get one chance to get the care right for someone at the end of their life. Yet, currently, people are all too often failed by a system that is not equipped to allow them to choose where they want to die. Recent analysis shows that 91% of cancer patients in England who die in hospital wanted to die elsewhere, with 65% wanting to die in their own homes.⁷ Currently, only 29% of people with cancer are able to be at home when they die.⁸

Access to basic social care services not only enhances someone's quality of life but is also vital if people are to have a genuine choice at the end of life. Services offered might include:

- help with personal care such as washing, cleaning teeth and dressing
- assisting someone in and out of bed or helping them to turn over in bed
- meal preparation, shopping, prescription collection
- carer support, to help a carer go out and complete tasks away from the home, or have a break to help them continue with their caring role
- small tasks around the home, such as responding to mail, putting the rubbish out, pet care.

Help with these relatively simple things, at such a difficult time, can reduce the pressure felt by families and carers and help them provide the care their loved one needs to stay at home. However, despite the significant difference social care can make, too often people are not given the opportunity to access it.

'It is very, very simple tasks that can flummox people [...] carers can manage an awful amount but there will be one thing that is the last straw that [makes] you think, "I can't resolve this alone." If there isn't a response then, your default position is back to hospital.

'Meal preparation, getting the laundry done, help with the bins, those kind of things aren't extensive care packages but [are] the important things people need help with.'

Tes Smith, Macmillan Social Care Lead⁹

3 The case for change

Removing barriers and encouraging integration

The PCFR,¹⁰ National Audit Office¹¹ and Demos¹² all highlight that the process for accessing state-funded social care is complicated, lengthy and separate from accessing the healthcare system. The PCFR states, 'This impedes the coordination of the services and the delivery of an integrated service for patients'.¹³ For people who may only have weeks to live, this fragmentation leads to delays that can prevent them receiving the care they need to die in the place of their choice.

'Too many patients at the end of life languish in hospital. They don't want to be on busy wards sometimes with a lack of privacy, dignity and respect, waiting for the services they need to get home and die in the place of their choice.'

'When someone is identified [as being] at the end of life, they must first be screened out of being eligible for healthcare before they can access social care. This significantly delays people getting the support they need to get them home to die.'

Jan Bolton, Macmillan Social Care Coordinator¹⁴



Complex assessment processes, separate budgets and poor communication lead to fragmentation between health and social care services. This results in delays and leads to people dying on expensive hospital wards and not in their place of choice.

In 2012, Macmillan commissioned a poll of health professionals to gain further insight into what they thought was preventing people at the end of life from accessing social care.¹⁵

- **97%** of healthcare professionals surveyed agreed that a lack of financial integration between health and social care is an important barrier preventing patients from receiving appropriate social care at the end of life.
- **92%** of healthcare professionals surveyed agreed that not identifying patients as being at the end of life is an important barrier preventing them receiving appropriate social care services.
- **97%** of healthcare professionals surveyed agreed that the complexity of and the time it takes to complete social care needs assessments is an important barrier preventing patients receiving appropriate social care at the end of life.

We believe that removing the social care means test for people in the final months and weeks of life would encourage these barriers to be addressed and for health and social care integration to be front of mind.

'We really needed some support with the practical side of life. Adrian struggled with even the most basic of tasks, such as tying his shoelaces.'

'I was working full-time while trying to see as much of him as possible, and my mum was trying to keep our family business going at the same time as caring for Adrian.'

'As a family, we really needed that extra support to give us more quality time with Adrian in his final weeks of life.'

Vikki, who cared for her dad, Adrian, at the end of his life

Macmillan also commissioned 20 in-depth interviews with health and social care commissioners to hear their perspectives on social care at the end of life. Many interviewees highlighted barriers that prevent people getting good quality end-of-life care. For example, one commissioner stated that:

'Ideally, yes, we would like to see those services free at the point of delivery, because then they would complement our NHS services better and we could get a better and more seamless service in place.'

A health commissioner from the Midlands

The weight of support

The statistics highlighted here demonstrate the weight of support from decision makers and NHS staff for introducing free social care for people in the last weeks of life.

OVER 99%

of health professionals surveyed agreed that people with cancer at the end of life should be supported so they can die at home, if this is what they want.

9 OUT OF 10

MPs believe their constituents should be entitled to die in the place of their choice.

7 OUT OF 10

MPs believe social care should be provided free of charge for people at the end of life, allowing them to die at home, if this is what they want.

8 OUT OF 10

health and social care professionals agreed that providing end-of-life care, including social care, in the community would save the NHS money through, for example, swifter discharge and reducing unplanned emergency admissions enabling more people to die at home.

OVER 96%

of health professionals surveyed agreed that social care, as part of an integrated package of care is crucial for keeping people out of hospital.

The moral argument

Macmillan's research has revealed a consensus among health and social care professionals, commissioners, think tanks, decision makers and opinion formers that providing people with the support they need, including social care, to allow them to choose where they die is the **right thing to do**.

Our survey of MPs shows there is support from across the political spectrum for our calls:

- **90%** of MPs surveyed believe their constituents should be entitled to die in the place of their choice
- **84%** believe the Government should do more to prevent people from dying in hospital, if this is against their wishes
- **70%** believe social care should be provided free of charge to people at the end of life, allowing them to die at home, if this is what they want.¹⁶

Additionally, most of the commissioners interviewed as part of Macmillan's in-depth research agreed with the principle of delivering free social care at the end of life.

'One of the key things that we've focused on for the past two years is trying to enable more people to stay at home, to die at home, than was previously the case. And that is done from a compassionate and caring point of view, and also there's a public benefit.'

A health commissioner from the north of England

'I think, actually, at the moment, the main argument would be around quality and around supporting people: morally supporting people to have respect and dignity at the end of their lives, so that they can actually choose how they want to die.'

A health commissioner from the Midlands

Over 99% of health professionals surveyed agreed that people with cancer at the end of life should be supported so they can die at home, if this is what they want. And 81% agreed that supporting patients so they can die at home instead of in hospital is less distressing for their families and carers.¹⁷

Lacey's story illustrates just how important it is to get care right for people at the end of their lives, and the impact it can have when people don't receive the support they need.

Lacey's story

Lacey's dad wasn't given the option to talk to a health or social care professional about where he wanted to die, but he had mentioned to his loved ones that he would like to be at home.

Lacey and her family struggled to support him at home but weren't made aware that social care support was something they could potentially access.

Lacey moved from Newcastle to Surrey to support her dad but was unable to spend any quality time with him, as her focus was on providing care to meet his basic needs.

Her caring role also had an impact on Lacey's own wellbeing. When her dad needed her support the most, both of them went without sleep for two nights.

On one occasion, Lacey fought for her dad to be admitted to a hospice for a short while, as he needed a level of care she was unable to provide. It was only by doing this that she had some time to look after herself and enjoy some quality time with him.

Had Lacey and her family been aware that social care support was an option, they would have asked for more help to improve the final weeks of her dad's life. Unfortunately, he needed more care than Lacey could provide at home, on her own.

Without this additional support, Lacey's dad died in hospital.

The cost-saving potential

We know emergency admissions at the end of life are a real and costly problem for the NHS. Recent analysis carried out by the National End of Life Care Intelligence Network supports this belief. It shows 89% of people who die in hospital are admitted as an emergency. Evidence from South West England also reveals that around 9.4 million bed days in hospital are occupied by people in the last year of life and who have been admitted as an emergency.¹⁸

The Nuffield Trust¹⁹ has shown that social care can help to reduce hospital admissions. In a recent study they found people with higher social care costs had lower hospital costs. Also, it was identified that the cost of caring for someone in hospital increases sharply in the final few months of life, especially for emergency care. The cost can be as much as £90,000 per person.

In contrast, social care costs are more predictable and constant, and home care is, on average, cheaper than care in hospital. This point was reiterated at Macmillan's parliamentary roundtable event.

'We looked at the patterns of local authority funded social care in the last 12 months of life. Though there is a slight increase it is nothing like the massive increase in hospital expenditure which led us to believe that, actually, the marginal costs of the social care at that time is going to be reasonably small compared to the costs within the system and certainly compared to the potential benefits to patients themselves and their carers.'

Dr Martin Bardsley, Director of Research, Nuffield Trust²⁰

The latest figures published by the National End of Life Care Programme²¹ also show that there is an estimated potential net saving of £958 per person who dies in the community rather than in hospital.

A health commissioner interviewed as part of Macmillan research agreed that, in their area, this research resonates.

'[Home deaths] are a lot cheaper. If we were doing this purely on economics ... it's a no brainer; it is a far more cost effective service.'

A health commissioner from the north of England

Health and social care professionals also agreed that providing free social care at the end life could save money: 81% of those surveyed by Macmillan agreed that providing end-of-life care in the community, including social care, would save the NHS money.²²

This view was also shared at Macmillan's parliamentary roundtable, where attendees discussed the value of early intervention and low-level support.

'As a palliative care social worker, I encouraged my clients and families to accept low-level support, which I would consider preventative. Perhaps a social care worker coming in on the morning, to ensure the carer could do the shopping ... it didn't seem like very much but it would manage things for that little bit longer.'

'In my view, that was less costly because it would maintain someone in their home for longer and support the carer.'

Philippa Graham, Chair of the Association of Palliative Care Social Workers²³

Our research findings are reinforced by Macmillan's practical experience of providing social care services. For example, a Macmillan social care coordinator in Northamptonshire provided support at the point of discharge to 228 patients in 2009/10. This resulted in 326 bed days saved through reductions in delayed discharge, and an estimated 140 bed days saved by preventing hospital readmissions.

This produced an overall saving of nearly £150,000, meaning that every £1 invested in the social care post generated £2.24 of monetised benefits to the healthcare system.²⁴

4 Conclusion

Today, people are too often let down at the end of life, when they are at their most vulnerable. If things remain the same, this situation is only going to get worse, because as our population ages, the number of people dying will increase year on year.

We simply cannot afford to continue to treat people in expensive hospital beds against their wishes. It is imperative that action is taken to change this, and that people have more choice at the end of life.

As this report has outlined, evidence suggests that providing relatively basic social care support can help to keep people out of hospital and provide genuine choice at the end of life. The research Macmillan has commissioned also shows strong support for the idea that providing free social care at the end of life is **the right thing to do** and **has the potential to save the NHS money**.

The Government has already stated that they see 'much merit' in the policy to provide free social at the end of life, which has been 'strongly endorse[d]' by the Joint Committee on the Draft Care and Support Bill.

Macmillan is now calling on the Government to deliver free social care for people who are on an electronic end-of-life care register before the end of this parliament.



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Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way, from the nurses and therapists helping people through treatment, to the campaigners improving cancer care.

Together, we are all
Macmillan Cancer Support.

For cancer support every step of the way call
Macmillan on **0808 808 00 00**
(Monday to Friday, 9am–8pm)
or visit **macmillan.org.uk**

Hard of hearing?
Use textphone 0808 808 0121, or Text Relay.
Non English speaker? Interpreters available.

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