CAN WE LIVE WITH HOW WE'RE DYING?

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

WE ARE MACMILLAN. CANCER SUPPORT

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Contents

FOREWORD

Watching someone you love die is an awful experience. But there is some comfort for families and loved ones from knowing that everything possible was done to honour the person's last wishes about where they want to die.

However, the health and social care system we have in England at the moment is preventing many people with cancer from having the death they, and their family, want.

For those who wish to die at home, it can be extremely difficult to draw a distinction between the support they receive from someone to dress their bed sores and the support they receive from someone to help them dress.

Yet the healthcare we all receive is provided free at the point of delivery, whereas our social care provision is means-tested and is often paid for by the person receiving the care.

For people at the end of life, trying to understand and navigate this complex system creates unnecessary stress and wastes precious time for families who know they may only have a few more days or weeks left.

As well as the financial cost to individuals and families, Macmillan believes there is also a significant cost to the taxpayer. People at the end of life who aren't helped with their social care are more likely to be admitted into an even more expensive hospital bed.

Providing free social care to people at the end of life therefore presents an opportunity to both support more people's choices about where and how they die while spending less money doing it.

The government should be applauded for the initiative it has shown in scoping out the feasibility of free social care at the end of life. But the idea was formally recommended by the Palliative Care Funding Review in 2011 and we are now in the final year of this government.

In setting out the economic case for the introduction of free social care at the end of life, we hope this report will provide the final missing piece in persuading ministers – with the support of all parties – to act now and do something which we passionately believe will help people at the end of life to die well.

Ciarán Devane

Ciarán Devane
Chief Executive
Macmillan Cancer Support

INTRODUCTION

Macmillan Cancer Support believes everyone with cancer at the end of life should be able to die well. This includes being able to die in the place of their choosing in as little pain and with as much dignity as possible.

For many people, this means wanting to die in the comfort of their own home surrounded by family and friends. We know from the National Bereavement Survey (VOICES) 2012 that respondents for those who died of cancer at home rated the overall quality of care highest and far higher than those who died in hospital[1].

But far too often this doesn't happen. In 2012 alone, **more than 36,000** people with cancer died in hospital in England when their wish had been to die at home. Their dying wish was denied. It is becoming increasingly clear that we need to radically change the way we support people at the end of life.

When assessing why it is that people are unable to die at home, difficulty accessing social care in the last few days and weeks of life is a recurring theme. Social care support at the end of life can provide some respite for carers and families looking after someone who is about to die. Crucially, this support can help prevent carers from struggling and can avoid crisis moments, which can all too often lead to people being readmitted to hospital via A&E.

The government has made some progress in assessing the feasibility of free social care at the end of life since the policy was formally recommended by the Palliative Care Funding Review in 2011. However, the lack of an economic assessment has been the major stumbling block to ministers making a final decision. In response, this report provides an assessment of the views of senior health and social care decision makers about the economic case for free social care at the end of life.

Choices at the end of life are important to everyone. Failing to satisfy those choices will stay with the friends and families long after someone's gone.

Macmillan is calling on all political parties to make free social care at the end of life a priority, both now and in their General Election manifestos.

Our research

We have commissioned three pieces of research around free social care at the end of life. These are a poll of 101 senior health and social care decision makers, in-depth interviews with 10 senior health and social care decision makers, and a second poll of a range of different health professionals.

We have also carried out an evidence review of the costs associated with not providing choice at the end of life.

In setting out the economic case this report is also designed to complement the recently published OPM report *How could free social care work in practice?* Together, the two reports provide the 'why' and 'how' in the case for making free social care at the end of life a reality as soon as possible.

WHAT IS SOCIAL CARE AND WHY DO PEOPLE AT THE END OF LIFE NEED IT?

A family never gets a second chance to get the death of a loved one right. When someone has the death they wanted, families and friends are able to grieve in the knowledge that they were able to grant the person they loved their last wish.

Alternatively, a loved one not dying in the place they wanted to can put a terrible emotional burden and sense of guilt on families and friends.

A good death includes making sure dying people have a choice about where they want to die, and for these choices to be actively supported and respected by the health and social care system.

We estimate that if this issue isn't tackled now by this government and the next, by the end of the next parliament in 2020

APPROXIMATELY 222,000

people living with cancer in England

WILL HAVE DIED IN HOSPITAL WHO WANTED TO DIE AT HOME[2]

This should be reason enough to make reforming end of life services an absolute priority.

'Dorothy was in hospital for six weeks at the end of her life and was admitted eight or nine times in her last year. During all this time no one told her she was at the end of life or asked her about what she wanted. No one offered us social care support. I believe it could have made a big difference because caring for someone can be so tiring and stressful, you never get to clock off.

We also couldn't get the home adjustments needed to care for Dorothy at home. My biggest regret was not getting Dorothy home to die. I'm going to have to live with that until I die.'

Alex, who looked after his wife Dorothy

What can social care at the end of life include?

When we talk about providing social care free to people at the end of life we are talking about people either on an end of life locality register or those who have a DS1500 form and are entitled to certain disability benefits under special rules, where doctors believe people are in their last six months of life.

A person with cancer who is within days or a few weeks of dying is often bed-bound or has very limited mobility. They are likely to require round-the-clock care and support with simple tasks such as preparing meals, eating and drinking, turning over in bed, getting dressed, having a wash, cleaning their teeth, and going to the toilet. There are also usually frequent visits at all times of the day from friends, family, district nurses, Macmillan professionals, the local GP and others.

Help with some of these relatively simple everyday tasks by a social care professional at such a difficult time takes a little bit of the pressure off families and carers. It not only helps them provide the care their loved one needs to stay at home, but gives them the chance to spend as much time as possible with the person who is dying.

We recognise that providing free social care isn't the only change needed to ensure people at the end of life have the best chance possible of having the death they want. But we do think it is a crucial part of a package of reforms we would like to see. We talked about some of the other changes needed in our October 2013 report *Time To Choose*.

'After almost four years being cancer-free, Dave's melanoma returned and he was given a terminal prognosis of just six to nine months. Right from the start he said he wanted to die at home, despite not really knowing what that meant.

He deteriorated very quickly and getting home support was tough. He was having seizures so my sister and I started staying over to help Dave's partner, but without support we eventually reached the end of our tether. He was admitted to a hospice, but after three weeks his condition improved and stabilised and he was able to go home.

However Dave's partner made it clear she couldn't handle things as they were before and that there needed to be more support to make this work. We began to have double carers four times a day and overnight support from Hospice at Home and Marie Curie nurses three to five nights a week.

Dave's desire remained to die at home, right until the end. But it was frightening at times. Navigating such a complex system to make it happen needed the support of professionals. It was just all so disconnected.'

Marie helped care for her brother, Dave

Why aren't people accessing social care at the end of life?

Despite the significant difference social care can make, too often people are not given the opportunity to access it. Many people think that social care at the end of life is free but in many cases it is means-tested.

The Fast Track Pathway of Continuing Health Care (CHC) is a package of health and social care funded by the NHS which can help address the needs of those at the end of life, helping them to receive care in a place of their choosing. However, as we set out later in this report, in many areas it is not working well enough.

We believe that the social care means-test is a barrier to accessing social care for people at the end of life in the following ways:

1. **For care at home services, only people with assets and savings of less than £23,250 are likely to get free social care (although some local authorities may still ask for payment below this level).**
2. **For those with assets of more than £23,250, accessing these assets or savings quickly enough can be difficult during a highly emotional, physically exhausting and stressful period in their lives.**
3. **Assessment for means-tested social care is often a bureaucratic and lengthy process when people need the support put in place quickly to leave hospital or prevent readmission.**
4. **The different funding structures for health and social care create perverse financial incentives for the two systems to compete against each other rather than to work together in the best interests of the person who is dying.**

We recognise the significant financial pressures likely to be facing the NHS and social services over the next decade and beyond. But Macmillan believes that the NHS is already spending tens of millions of pounds every year on hospital-based care that people with cancer and their families do not want and, for most, would not need if community-based services were in place as an alternative. So if there is not more money available we think existing funding could be far better spent providing social care services for people at the end of life.

'It is incredibly hard to draw a distinction between what is health care and what is social care around the end of life. There is little logical division between what is means-tested under social care and what is free at the point of use as health care.'

Commission on the Future of Health and Social Care in England. *A new settlement for health and social care (Interim Report)*, April 2014

GROWING POLITICAL SUPPORT

Growing cross-party political support strongly suggests that now is the right time to introduce free social care at the end of life.

The Dilnot Commission, the recent Care Act, the government's Better Care Fund and the opposition's commitment to 'whole person care' all indicate a broad political consensus to see a more closely integrated health and social care system. Such a system could see far more services provided in the home and community and could mean hospital care is seen as the last resort rather than the first.

We also think there is a broad political consensus about the need to give people far more choice about their care at the end of life.

Within this context, we have seen growing political and expert support specifically for the introduction of free social care at the end of life.

JULY 2011
Palliative Care Funding Review recommends removing the need for a social care means-test assessment for patients on an end of life locality register.

JULY 2012
The government says it sees 'much merit' in the principle of free social care at the end of life in the Care and Support White Paper.

MARCH 2013
The Joint Committee reviewing the Draft Care and Support Bill calls for free social care at the end of life to be introduced at the 'earliest opportunity'.

APRIL 2013
Macmillan publishes *There's no place like home* report which shows that 84% of MPs surveyed believe the government should do more to prevent people from dying in hospital, if this is against their wishes, and 70% believe social care should be provided free of charge to people at the end of life, allowing them to die at home if it is what they want.

SEPTEMBER 2013
Andy Burnham, Shadow Secretary of State for Health, says in his Labour Conference speech 'Too many people, against their wishes, end their life in hospital. So we work to give people the right to be at home, with family around them and social care free as part of that'.

JANUARY 2014
Asked during the Care Bill's passage through parliament whether he wanted to see free social care at the end of life Norman Lamb, Care Services Minister, says 'I am determined that we achieve that objective'.

APRIL 2014
Interim report by the Commission on the Future of Health and Social Care in England led by Kate Barker for The King's Fund says 'It is incredibly hard to draw a distinction between what is health care and what is social care around the end of life' and concludes that there is a 'strong case' for free social care at the end of life.

VIEWS FROM SENIOR HEALTH AND SOCIAL CARE DECISION MAKERS

Until now, the views of the people who actually make the decisions about how to spend health and social care budgets to deliver end of life services on the ground have been largely missing from the discussion around free social care at the end of life.

We therefore commissioned ICM to conduct a qualitative and quantitative study in April 2014 with senior health and social care decision makers involved in end of life care. They conducted 101 online surveys and 10 in-depth phone interviews to assess views on free social care at the end of life.

It is clear that senior decision makers care deeply about trying to deliver the best possible services to people living with cancer and to their families. And they are equally frustrated that the current system does not allow them to do that.

'I'm absolutely passionate about people being able to die at home. Many people are constantly surprised that they have to pay for the social care component. There are lots of families that struggle on and struggle on without using care because of how much it's going to cost them.'

Former Palliative Care Team Service Lead

In particular, the research identified bureaucracy and a lack of clarity between the health and social care systems as a major barrier to accessing high quality social care. Although CHC Fast Track Funding was recognised as having some value, the consensus was that more often than not, it is not working in practice. Issues identified included struggling to get CHC Fast Track funding agreed and delays in the care packages being provided.

'There are frequently disputes ... between local authorities, who have a responsibility for social care, and the health sector, when it comes to end of life care. Who pays? For too many people that dispute goes on in the background whilst they're living through their last few days. They will hopefully never know about it, but there is a real lack of clarity over the funding arrangements for the last six weeks of care.'

Executive Director of Care and Health Services

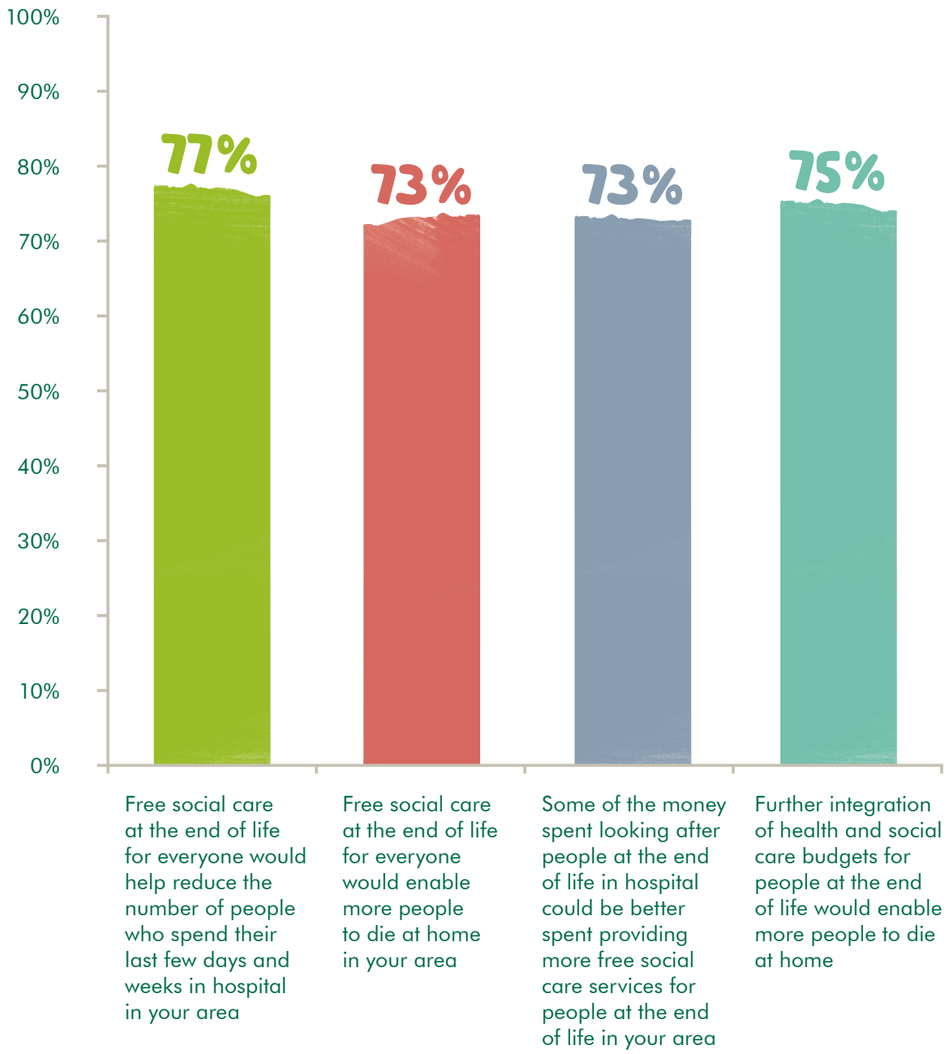
'I don't think we have sorted out the problem with Continuing Health Care funding ... there's provision under the national framework at the moment to fast track decisions for Continuing Health Care for people with end-of-life care needs. Whilst I've got evidence to show that is being applied to some appropriately, I've got a good reason to believe it's not applied as widely as it should be.'

Senior Manager, Adult Social Care

The majority of participants felt that better integration of health and social care at the end of life is considered the best way to fix this. There is consensus that free social care at the end of life as part of an integrated service would save money and deliver a far better service for patients, families and carers.

Nearly three quarters (73%) of respondents agree that some of the money spent looking after people at the end of life in hospital could be better spent providing more free social care services for people at the end of life in their area. The same proportion also agree free social care for everyone at the end of life would enable more people in their area to die at home. **75%** of respondents feel that further integration of health and social care budgets for people at the end of life would enable more people to die at home.

From the results of the study it is clear that there is a strong consensus among senior health and social care decision makers for the need for better integration between the health and social care systems, including the introduction of universal free social care at the end of life.



Question asked: 'How much would you agree or disagree with the following statements?'
Base: All respondents (n=101).

ESTIMATING THE ECONOMIC CASE FOR FREE SOCIAL CARE AT THE END OF LIFE

Like the senior health and social care decision makers surveyed, we believe there is a potential for money to be used more effectively to meet the needs of patients by providing free social care at the end of life.

The government is expected to publish its assessment of the economics of free social care at the end of life later this year. Ahead of that, we are setting out what we believe is a credible estimate – based on expert assumptions and available data – of the potential savings were social care to be provided free for people at the end of life.

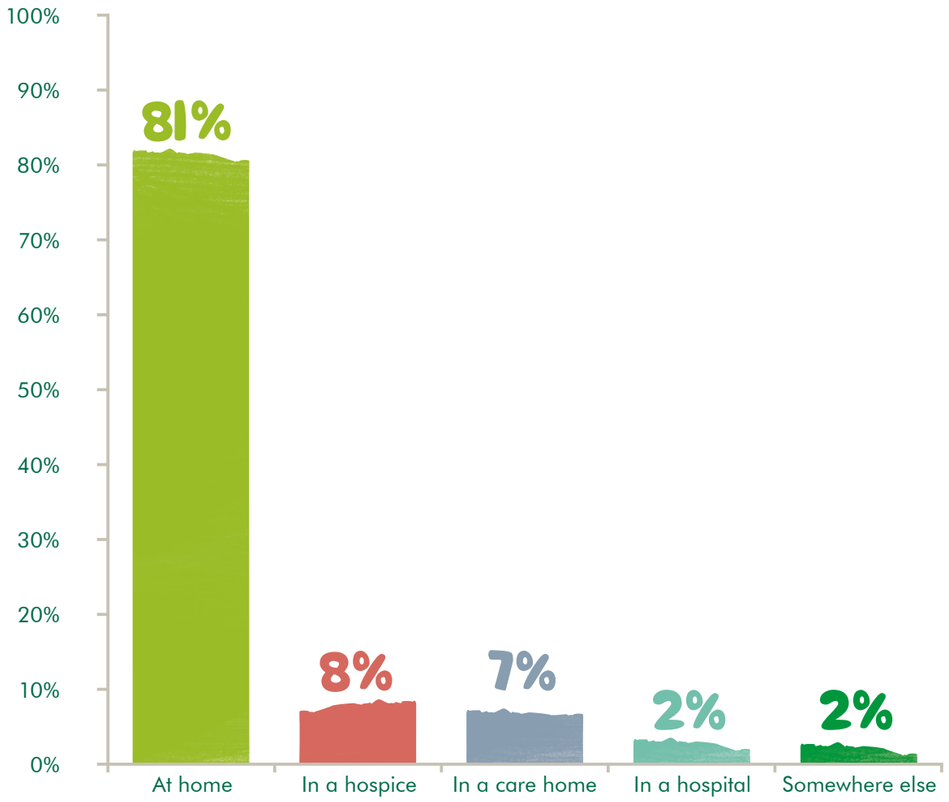
In order to do this we estimated:

- the number of people who die in hospital who would prefer to die at home
- the average length of final stay in hospital at the end of life
- the average cost of these final stays
- how much social care at the end of life costs on average
- therefore, how much could potentially be used more effectively across health and social care.

Numbers of people affected

This is an issue that does not just affect people with cancer. Our analysis concludes that providing a comprehensive care package for all people who want to die at home but who actually died in hospital could cost significantly less than is spent on their hospital care.

We know that **81%** of people who died in England in 2012 and expressed a preference said they wanted to die at home. In that year there were **just under 229,000** deaths in hospital across England[3]. We therefore estimate that **181,780 people** died in hospital in 2012 who would have preferred to die at home.



Question asked: 'Preferred place of death?'
Source: *The 2012 National Bereavement Survey* (VOICES)[4]

Average length of final stay and estimated cost to NHS

Hospital Episodes Statistics Data for 2011–12 shows that the average length of stay in hospital per admission that ends in death is **12.9 days**[5]. Patients approaching the end of life will need varying levels of care, depending on the complexity of their condition. The National Council for Palliative Care estimates that the proportion of end of life patients who need specialist palliative care is **45–47%**, and the proportion is often higher for those dying with cancer[6].

The Personal Social Services Research Unit indicates an average cost of **£340 per day** for inpatient specialist palliative care[7], and National Audit Office figures indicate generalist hospital care costs **£250 per day**[8]. Using these figures we can assume that the average cost for an individual's final stay in hospital would be **approximately £3,770**.

By extension we therefore estimate that the NHS spent **approximately £685 million** on hospital care at the end of life for all people who died in hospital in 2012, but who wanted to die at home.

How much could free social care save?

We know there would be a cost for the care needed in a community setting to support these people to die at home. Social care forms just one part of a suite of support measures which enable people to die at home. Marie Curie research into costs for all end of life care estimates that a comprehensive package of community support costs **£145 per day**, with social care comprising **just £27** of this[9].

Applying this to the **181,780 who died in hospital** when they would have preferred to have died at home, and taking the **12.9 days** as a proxy, we can calculate that the equivalent cost to have a package of community palliative care would be **£340 million**. It is worth noting that social care is part of that package and accounts for **£63.3 million** of that cost.

By extension we therefore estimate that if all of the **181,780 people** who wanted to die at home but who died in hospital in 2012 were able to die at home, then approximately **£345 million per year** of NHS money could be used more effectively.

The above estimates are the total cost across all conditions. Of those who died from cancer we estimate that, in 2012, **36,400 people** who died in hospital would have preferred to die at home in England. We therefore estimate that the NHS spent **£137 million** on hospital care at the end of life for cancer patients who had said they wanted to die at home in 2012 alone.

The equivalent cost to have a package of community palliative care including social care would be **£68.1 million**.

We therefore estimate that if all

36,400 PEOPLE WITH CANCER

were supported to die at home, then approximately

£69 MILLION OF NHS MONEY

currently spent on hospital care for these people

COULD BE USED MORE EFFECTIVELY

The most recent Nuffield Trust report *Use of health and social care by people with cancer*[10] supports our estimations. Of the cohort of people with cancer at the end of life, those in the last three full months had 20% more emergency admissions, and over 60% more elective admissions and outpatient attendances than people with other health problems at the end of life. As well as this, a third of people with cancer had an emergency admission in the last full month of life. **They estimated that the total hospital costs for this group were more than five times the cost of social care provided in the final year of life.**

Recognising the limitations in our estimates

We have developed these figures as a credible estimate to inform debate on this issue. However, we recognise that the figures have limitations.

National data about the costs of end of life care is lacking and people's preferences for where they want to die can change.

The level of specialist, or generalist, palliative care people will need as they approach the end of life will vary. We calculated the costs associated with the **53%** of those in hospital at the end of life but not receiving specialist palliative care to be receiving generalist hospital care. However, this is likely to be an underestimate given the increased likelihood of some level of palliative care in addition to standard care.

Research detailing the average cost of inpatient specialist palliative care also varies significantly. Some estimates use a figure of **£425 per day**[11]. We decided to use the average cost of **£340 per day** calculated by the Personal Social Services Research Unit as this was the more up to date figure.

We also know that even if social care were universally available in the community some people at the end of life would still have a clinical need to die in hospital. This has not been factored into the calculations because we are unaware of any national data that sets out the proportion of people for whom this would be the case. However, based on published case studies, we are confident that such a proportion would be relatively small. For example, the Paul Sartori Foundation in Pembrokeshire, which provides a Hospice at Home service reported that in 2012–13, of the approximately **205 people** who used the service, **94%** were able to die at home, while the previous year this proportion was **89%**[12]. Similarly, a study found that **71%** of people cared for by the Midhurst Macmillan Specialist Palliative Care Service in 2010–11 had been able to die at home[13].

Three in four health professionals polled by Macmillan in June 2014 estimated that, if comprehensive end of life care services were available in the community, no more than **30%** of people would have a medical need to spend their last few days in hospital. Just under half estimated that this figure would be no more than **20%**[14].

We also recognise that there would be additional transition costs involved in moving from a hospital-based care service to a community-based service.

'In July 2008 – a month after my wedding – my dad, Tony, was told he "probably" had lung cancer. We had to wait two weeks for hospital tests and two more weeks for the results. He did have cancer and it had spread to all of his organs.

The wait was intolerable but the diagnosis was devastating. He was offered palliative chemotherapy but after one session became desperately ill and I had to rush him to hospital. But Dad wanted to die at home.

Fortunately, we had all the facilities and help we needed. We talked about holidays, gardening, childhood activities, and the grandchildren, and played music to him in his new bed in the front room for the last two weeks.

The GP, district nurses, auxillary nurses and carers were the most amazing, sensitive helpful people we could have wished for – a human safety net. To all these people we will be eternally grateful.'

Tessa helped look after her dad, Tony

CONCLUSION

Last autumn Macmillan exposed the fact that every day around 100 people with cancer die in hospitals in England having said they wanted to die at home.

If nothing is done, by the end of the next parliament in 2020 we estimate that

APPROXIMATELY 222,000

people living with cancer

WILL HAVE DIED IN HOSPITAL IN ENGLAND

having said they

WANTED TO DIE AT HOME

If this happens it will be nothing short of a national scandal.

We now know that by not integrating health and social care services for people at the end of life, and by preventing free access to social care, senior health and social care decision makers believe we are not using scarce public funding as effectively as we could be. We are also preventing people at the end of life from making the vitally important choices they want to make about where and how they die.

We fully recognise that the lack of robust end of life data makes it difficult to estimate how much money is being spent on hospital care for people who have said they wanted to die elsewhere, and how much care based in the community would cost instead. However, we believe the estimates we have set out still help us move the case forward for free social care at the end of life when considered alongside the clear assessment of senior health and social care decision makers and growing evidence from elsewhere.

It is clear to us that currently the majority of cancer patients are dying where they do not want to be, and do not need to be. The current system is failing to honour the choices of people at the end of life and costing the NHS significantly more than it needs to.

Macmillan believes everyone involved in delivering end of life care has a fundamental moral duty to give people the best chance possible to die well. It is time for the argument that we cannot afford to provide free social care at the end of life to be turned on its head. We cannot afford to **not** introduce it.

End of life should not mean end of choice. We want this government to take the next step and commit its support for free social care before the end of this parliament. But it will need to be the next government – after the May 2015 General Election – which will implement the policy on the ground. Therefore, it is imperative that all political parties commit to supporting free social care at the end of life in their General Election manifestos.

Only then can we be sure that whoever makes up the next government, free social care for everyone in England at the end of life will finally become a reality.

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[1] Office for National Statistics. *National Bereavement Survey (VOICES)*. 2012

[2] Macmillan estimates that, between 2015 and 2020, 305,000 people will die from cancer. *National Bereavement Survey (VOICES)* from 2012 showed that 73% of people with cancer died in hospital when home was their preferred place of death. We applied this proportion to the above estimate of people who will die from cancer in the period 2015-2020 to estimate that, if this proportion remains the same, 222,650 people would die in hospital when they would have preferred to die at home.

[3] Office for National Statistics. *Mortality Statistics: Deaths Registered in 2012 (Series DR)*. 2012

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[12] OPM. *How could free social care at end of life work in practice?* 2014

[13] Noble et al. Can comprehensive specialised end of life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK. *European Journal of Cancer Care*. 2014

[14] Research Now/Macmillan Cancer Support online survey of 152 health professionals who deal with cancer patients (GPs, oncology consultants and oncology nurses). Fieldwork conducted June 2014. Survey results are unweighted.

The UK is facing a cancer crisis. By the end of the next government's term in 2020, almost half of us will have to face cancer sometime during our lives. And while the majority of us will receive a good standard of care, this sadly isn't the case for everyone.

We urgently need to change this.

Our survival rates are among the worst in Europe – not least because thousands of us are diagnosed too late. And many thousands more are treated with a lack of compassion or denied the right to die where we want, with dignity. If we're struggling to ensure everyone receives a good standard of care now, how will we cope as the number of us diagnosed with cancer grows?

Next year's General Election is our chance to make sure the new government tackles this looming crisis. Without urgent action, not everyone with cancer will get the care that's right for them.

No one should face cancer alone.

Help us raise standards of cancer care and make sure it is a priority for the next government.

Find out more at **macmillan.org.uk/GeneralElection2015**

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