

TIME TO CHOOSE

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MACMILLAN.
CANCER SUPPORT**

Making choice at the
end of life a reality

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Foreword

Having a genuine choice about where to spend the last days and hours of your life and receiving the support to ensure that choice is met, is hugely important to people approaching the end of life. The right options and support can also have a lasting positive impact on their carers and families.

Despite this, while nearly three quarters (73%) of people with cancer would prefer to die at home, less than a third (29%) are able to do so.¹ Macmillan estimates that in 2012, this meant 36,000 cancer patients died in hospital when they would have preferred to die at home.²

This is not because meeting end of life preferences is unfeasible or unaffordable, but because services are not organised around the needs of individuals and their families. This must change.

The NHS Mandate sets an ambition for the NHS in England to deliver a 'globally recognised' standard of end of life care. In addition, the Government has committed to move towards a 'national choice offer' to ensure those people who want to die at home get the support they need.³

These commitments are welcome. However, they will not be achieved without significant changes to how care at the end of life is delivered. Crucially, care and resources need to move from hospitals into the community in line with people's preferences.

This will only happen if all those involved in end of life care – the Government, the NHS, providers, commissioners and

professionals – share the same ambition; to deliver integrated care that meets the needs and wishes of those approaching the end of life and their loved ones.

We have a significant opportunity now to set out both a renewed commitment to improving choice at the end of life and a clear vision of how it can be achieved. The Government has promised to review when a 'national choice offer' can be introduced and what needs to happen to make it a reality. Alongside this, NHS England is refreshing the National End of Life Care Strategy.

This report is Macmillan's initial contribution to this work. It seeks to set out the key barriers to choice at the end of life and recommendations for change at a national level.

Some of the solutions are clear, such as making social care free for people at the end of life, and some will require further discussion and thinking for change to happen, such as reforming how incentives are used in end of life care.

I look forward to discussing the themes raised in this report with all involved in end of life care in England and to working together to make choice at the end of life a reality.



Ciarán Devane
Chief Executive
Macmillan Cancer Support



Executive summary

When asked, most people approaching the end of life say that they would prefer to be cared for and die at home. However, currently nearly half of all people die in hospital.

We know that the experience of dying in hospital, often following an emergency admission, is likely to be worse than dying elsewhere, such as at home or in a hospice. We also know that end of life care in hospital is often more costly than care in the community.

This report seeks to set out the barriers that prevent people from having genuine choice at the end of life and makes recommendations for improvements. It includes:

Why choice is important – the benefits of real choice to people approaching the end of life and their carers, the reduced demands on hospitals and potential financial savings

The barriers to choice – the lack of identification of people approaching the end of life, poor planning and coordination of care and limited access to 24/7 community services, social care and support for carers

Solutions and recommendations for improving choice at the end of life – the need for wider use of electronic palliative care registers, greater access to 24/7 community services, improved signposting for carers and free social care at the end of life

Although this report is aimed at national decision-makers in England, we anticipate that many of the findings and recommendations will be relevant to colleagues in the rest of the UK.

The report was produced following an evidence review, a focus group with bereaved cancer carers, a workshop with commissioners and interviews with end of life experts.

Our vision is that people who are nearing the end of their life will be supported to make decisions that allow them and their family or carers to be prepared for their death.

Their care will be well coordinated and planned so that they die in the place and in the way that they have chosen.

1 Why is choice at the end of life important?

Delivering choice about where people are cared for at the end of life must be a priority for those involved in health and social care in England because:

Most people are not able to die in their preferred place

Nearly half of people are still dying in hospital when a majority would prefer to die at home.

	Home	Hospice	Care Home	Hospital
Preferred place of death	81%	8%	7%	2%
Actual place of death	23%	7%	22%	48%

Source: The 2012 National Bereavement Survey (VOICES)⁴

For people approaching the end of life, being cared for and dying at home in a familiar environment and surrounded by loved ones is often hugely important.

'He wanted to maintain his dignity and his privacy...although undoubtedly in the hospice he had his own room and the care that he needed... he wanted to be in his own home.'

Anna, who cared for her husband at the end of life

Experiences of dying in hospital are often poor

People are most likely to have a bad experience of dying in hospital, compared to dying at home, in a hospice or in a care home.

The National Bereavement Survey 2012 (VOICES) shows that over half of respondents whose loved one died at home (53%) or in a hospice (58%) rated the quality of care in the last three months of life as 'outstanding' or 'excellent'. But the same figure for those who died in hospital was only a third (34%).⁵

'It was familiarity of family and environment, but also it was sheer fear that if she went into hospital she would be totally neglected.'

Nikki, who cared for Audrey, her mum, at the end of her life

It can reduce unnecessary emergency admissions

89% of those who die in hospital do so following an emergency admission.⁶

This represents a poor outcome for patients and places a costly and unnecessary strain on already stretched accident and emergency departments.

As the number of people who die each year increases over the next decade⁷, it is likely that the current model of care will become increasingly unsustainable. Delivering end of life care in line with people's preferences could help reduce the number of emergency admissions.

It can save money

There is good evidence to suggest the cost of care could be reduced if it was more closely aligned with people's end of life preferences.

Potentially, there are net savings of £958 for every person who dies in the community rather than in hospital, according to figures published by the National End of Life Care Programme.⁸

2 Barriers to choice

This section summarises some of the main barriers preventing people at the end of life from being cared for in their preferred place.

There are multiple issues that prevent people from being cared for and dying in their preferred place. Below we summarise the most significant barriers.

Where relevant, we have included quality statements from the National Institute for Health and Care Excellence (NICE) End of Life Care Quality Standard for Adults to demonstrate the care that people at the end of life should expect, but are not always receiving.⁹

Identification and conversations

NICE quality statements:

- People approaching the end of life are identified in a timely way
- People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

A person's chance of dying in their preferred place improves if professionals involved in their care identify early on that they are approaching the end of life and talk with them about their care and preferences.

38% of people approaching the end of life were either probably or definitely unaware that they were likely to die.¹⁰

However, too many people are not being identified in a timely way. Often, people are not identified at all.¹¹

In addition, many professionals lack the confidence to have conversations about the end of life with people in their care. A Dying Matters pilot study found that 60% of GPs rated themselves either 'not confident' or 'not very confident' in initiating conversations about end of life.¹²

'We both agreed, yes at home, and she didn't want to be resuscitated. So we were in a position where we were happy to talk to whoever would be responsible for this...In the end, I found myself actually explaining to the doctor she was dying... In terms of planning, I just felt that the health professionals were not themselves comfortable enough with death to be able to have conversations with us. That really has an effect on how you can plan someone's end of life.'

Nikki, who cared for Audrey, her mum, at the end of her life

Lack of planning and coordination

NICE quality statements:

- People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment
- People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

When asked whether community services worked well together – only 45% responded 'yes – definitely'.

When asked whether hospital services worked well together with GP and other services outside hospital – only 33% responded 'yes – definitely'.¹³

Care for people at the end of life will often involve multiple health and social care providers, working across commissioning boundaries and in a variety of care settings. Therefore, good communication and coordination between professionals is critical. However, bereaved carers told us that the planning and coordination of their loved ones care was often extremely poor.

Bereaved carers also reported that they, or the person they were caring for, were frequently required to repeat information to different professionals. As a result, there was little confidence that those professionals had recorded or shared information about their loved one's condition or care.

'You appreciate you have to wait around for things and people can't act instantaneously. But just information sharing, surely there's got to be some central bit of information that says "yes, I know who you are, I'm expecting you"; just to give you that bit of confidence.'

Anna, who cared for her husband at the end of life

There is evidence to suggest that the use of advance care planning (ACP) to establish a person's wishes around their care at the end of life can increase the likelihood of those wishes being met.¹⁴ However, anecdotally we know that uptake of the use of ACP across England is variable.

Likewise, Electronic Palliative Care Coordination Systems (EPaCCS), which hold information about a person's care and preferences that can be shared with different professionals are crucial to good coordination.

Where implemented, EPaCCS have helped as many as 80% of people registered to die in their preferred place.¹⁵ A recent evaluation carried out by NHS Improving Quality estimated yearly savings of up to £133,200 where EPaCCS are used.¹⁶

However, despite recent progress, many areas in England are still not covered by EPaCCS.¹⁷

Skills and roles within the community workforce

NICE quality statement:

- Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people.

If more people are to be able to die in the community in line with their preferences, then the community workforce will need the appropriate resources and skills. In particular, the role of community nurses will be crucial.

However, there are concerns that a changing skill mix within the community workforce will impact the quality of end of life care for people who choose to die at home. For instance, the number of district nurses, who have played an important role in supporting people at the end of life, is declining.¹⁸

The older age profile of the community workforce is also likely to pose challenges in the near future as many of those professionals currently practicing retire.¹⁹

'I had to take that advocate and leadership role because everybody has a little bit of responsibility for something but nobody actually has any overall control. You think it might be the GP but they've got nothing to do with us, so as a relative we have to take that leadership role. But you don't actually realise that that's what you're going to have to do.'

Nikki, who cared for her mum, Audrey, at the end of her life

Bereaved carers have also highlighted the lack of a named professional in the community who is responsible for coordinating the care of their loved one. In these circumstances, carers have had to assume the role of a 'key worker' and take responsibility for joining up care.

Lack of access to 24/7 community services

NICE quality statement:

- People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

Only 19% of people who died at home received adequate pain relief 'completely – all the time' in the last 3 months of life.²⁰

24/7 community nursing and out-of-hours access to other services plays an important role in reducing unnecessary emergency admissions. Without them, people are often unable to die at home in line with their wishes.²¹

Community nurses provide vital medical support and pain relief, such as managing a syringe driver or putting in a catheter, which would otherwise have to be provided within hospital.

Yet access to these vital services in the community at all times of the day or night remains a lottery for people who wish to be cared for and die at home.

The absence of 24/7 community nursing locally is described as 'stark' by the Palliative Care Funding Review²² – despite the National End of Life Care Strategy²³ highlighting this service as a priority.

In 2010, nearly half of Primary Care Trusts (44%) did not provide a 24/7 nursing service for all patients at the end of life.²⁴ Anecdotal evidence from patients, commissioners and clinicians suggests that in the transition to Clinical Commissioning Groups (CCGs), little progress has been made.

Access to other routine out of hours services is also a significant issue. For example, a joint inquiry by the Royal College of General Practitioners and the Royal Pharmaceutical Society in 2011 found that 'access to palliative care medicines during out of hours continues to be difficult in most areas.'²⁵

Lack of access to social care

NICE quality statement:

- People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

Receiving vital social care services at the end of life can be crucial to allow people to remain at home. The support provided by social care is often help with straightforward but essential tasks, such as washing and dressing, assisting someone in and out of bed, meal preparation or prescription collection.

However, many people who desperately need it, go without this support.

A recent Macmillan report outlined that the lack of social care support is often caused by complex assessment processes or fragmentation between health and social care services.²⁶

In response to a Macmillan survey, 97% of healthcare professionals agreed that the complexity of, and the time it takes to complete, social care needs assessments was an important barrier preventing patients receiving appropriate social care at the end of life.²⁷

'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.'

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

Lack of support for carers

NICE quality statement:

- Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Only 5% of cancer carers have received a Carer's Assessment.²⁸

When someone expresses a wish to die at home, it is often because they have a relative or friend who is available to be their carer.²⁹ As a result, carers will often take on the vast majority of personal care responsibilities for someone who is approaching the end of life and wants to die at home.

Evidence suggests that the needs of cancer carers are greatest at progressive illness and end of life stage.³⁰ Therefore, it is not surprising that the lack of support for carers is a key reason why cancer patients who had chosen to die at home are still being admitted to hospital in the last days and hours of life.³¹

Despite the vital role that carers play in ensuring end of life care wishes can be met and in relieving the pressure on the health and social care system, many are still receiving little or no support.

Macmillan research found that 47% of those looking after someone with cancer felt they needed support that they weren't getting.³² A lack of identification and recognition by health and social care professionals has been highlighted as a barrier to carers accessing vital information, advice and support.

A Carers Week survey in 2012 found that over 70% of carers come into contact with healthcare professionals during their journey. However, only 11% were identified as a carer by a healthcare professional.³³

'I think that they thought "everything's ok, she's coping" because my mum was a healthcare assistant for many years and they'd seen how she looked after my dad. But inside she was an absolute mess. I think it was a shame because more personalised and regular contact with her probably would have shown the cracks on the wall and therefore they would have been able to tailor things to her needs a lot more.'

Zoë, who cared for her dad at the end of life

Commissioning and incentives

Commissioners who attended a recent Macmillan workshop highlighted the current funding of end of life care services as a particular challenge in relation to supporting choice.

There is compelling evidence emerging from the Quality, Innovation, Productivity and Prevention (QIPP) end of life care workstream about the savings that can be made by moving care from hospitals to the community.³⁴ However, commissioners highlighted that it is difficult to understand these savings locally because costs are often 'bundled' as part of a block contract with an acute provider. This makes moving resources to support patient choice difficult.

Commissioners also felt that incentives for improving end of life care are not aligned across providers and lacked a clear focus on delivering improved outcomes for patients, such as being cared for in their preferred place. For instance, there is no nationally applied Commissioning for Quality and Innovation payment (CQUIN) or Directed Enhanced Services payment (DES) for improving choice and quality at the end of life.

Additionally, the current Quality Outcomes Framework (QOF) indicators were widely perceived to not reflect best practice in end of life care.

3 Solutions and recommendations

Having examined the barriers to choice at the end of life, this section seeks to explore some of the solutions and make recommendations to address these barriers.

Improving planning and coordination

Recommendation: The Department of Health and NHS England should make a renewed commitment to the national implementation of EPaCCS and produce a clear strategy and timeframe for achieving this.

NHS England should prioritise investment for national roll-out within plans for the Integration Transformation Fund.

As discussed earlier, EPaCCS can play a key role in improving the coordination of care and ultimately choice at the end of life.

The National End of Life Care Strategy made a commitment that 'End of life care registers will be piloted and established to ensure that every organisation which will be involved in care is aware of a patient's wishes.'³⁵ However, despite some progress, five years on EPaCCS are still not available in all areas.³⁶

Commissioners who participated in a Macmillan workshop were clear about the need for a greater national focus on the implementation of EPaCCS. They agreed that this was particularly important given the need for integrated IT solutions.

NHS Improving Quality estimates the costs of implementing EPaCCS to be £21,000 per 200,000 population per year.³⁷ When considered across England, this would represent a modest investment.

The £3.8bn Integration Transformation Fund (ITF), announced as part of the 2013 Spending Review, has been established for projects, such as EPaCCS, that encourage better integration between health and social care, improve outcomes for patients and reduce emergency admissions.³⁸ We believe the ITF represents a significant opportunity to roll-out EPaCCS.

When implemented nationally, EPaCCS will provide a rich source of data that can be used to benchmark and compare outcomes for people at end of life across England and between different areas.

In addition, health professionals responsible for planning end of life care locally should ensure that advance care planning is a routine part of the care package offered to people approaching the end of life.

To promote the use of advance care planning, Macmillan has produced *Your Life and Your Choices: Plan Ahead*, a guidance booklet for professionals and the public in England and Wales.³⁹

Improving the workforce

Recommendation: The Department of Health should make training in end of life care a priority within the Mandate to Health Education England.

Health and social care professionals need appropriate support and training in order to deliver care that meets the needs and preferences of people approaching the end of life.

As a priority, the Mandate provided by the Government to Health Education England needs to prioritise training for end of life care. This will ensure a national approach to improving skills. Currently, the Mandate highlights the training needed to ensure people get the 'best start in life', but doesn't mention end of life care.⁴⁰

Undergraduates on medical, nursing and social care courses need better training in identifying and communicating with people approaching the end of life. Currently, there are concerns that their core training does not adequately equip them with these skills. Macmillan endorses the call for strengthening end of life training in undergraduate curricula in a recent report by Demos.⁴¹

Recommendation: Everyone approaching the end of life should have a named professional who is responsible for their care and ensuring, where possible, end of life care preferences are met.

It is important that professionals take responsibility for coordinating care for people at the end of life and ensuring their preferences are met. A person approaching the end of life may have a different named professional at different times as their needs change. But, importantly, each individual and their carers should always know who is responsible for their care at any one time.

The need for a named professional for every person at the end of life was a key recommendation of the Independent Review of the Liverpool Care Pathway.⁴²

Improving access to 24/7 community services

Recommendation: Through the Seven Day Services Forum, NHS England should explicitly address the provision of 24/7 services in the community (such as community nursing) that are vital to supporting choice at the end of life.

The Department of Health and NHS England must make wider implementation of 24/7 community services, particularly community nursing, a priority. Without concerted action to improve the availability of basic community services at all times throughout the day and night, people approaching the end of life will continue to be admitted to hospital unnecessarily and often against their wishes.

CCGs and local authorities have a fundamental role in ensuring that 24/7 services are in place to support people at the end of life. However, Macmillan also believes that given the lack of progress, greater national leadership is required.

The next phase of the review into Seven Day Services, led by the NHS England Medical Director, Sir Bruce Keogh, and the Seven Day Services Forum is a key opportunity to address the significant gaps in 24/7 community services.

Providing free social care to people at the end of life

Recommendation: The Government should commit to implementing free social care for people at the end of life by the end of the current Parliament.

Too frequently and for too long, patients have been the victims of the failure to integrate health and social care services. This is particularly true for people at the end of life who, as well as experiencing poorly joined up services, too often go without social care support altogether.

Providing free social care to people at the end of life is key to solving these problems and improving choice. This was a key finding of the Palliative Care Funding Review.⁴³

A coalition of end of life charities, including Macmillan, has made a powerful case in favour of free social care at the end of life. The Government response has been positive in that Ministers have recognised 'much merit' in the principle. But, so far, a firm commitment is still lacking.

Supporting carers by strengthening the Care Bill

Recommendation: The Care Bill should make clear that there should be a joint responsibility on health services and local authorities for identifying and signposting carers to information, advice and support.

The Care Bill is currently going through Parliament. The provisions in the Bill which increase the obligations on local authorities towards carers are a positive step forward.

However, there is a considerable gap in that there are no equivalent responsibilities on health services. This is a particular issue for people affected by cancer who are more likely to come into contact with health services than local authorities.

Currently, many carers are not being identified by the health services and signposted to support. This means that they cannot be assessed by local authorities or receive the support that they are entitled to.

Amending the Care Bill so that it is clear that health services have a responsibility for identifying and signposting carers is a vital first step to addressing this problem.

Improving commissioning and incentives

Recommendation: NHS England should explore with stakeholders how national incentives for end of life care can be aligned and clearly encourage improved outcomes for patients, such as being cared for in their preferred place.

Macmillan's workshop with end of life commissioners revealed significant confusion regarding the role of incentives in end of life care. It was felt that different schemes, such as Enhanced Services, CQUIN payments and the QOF, were poorly aligned, often inconsistently applied and not always adequately focussed on quality.

Therefore, NHS England should work with stakeholders to understand how the system of incentives for end of life care should be improved. This is particularly pressing

in light of the findings of the Independent Review of the Liverpool Care Pathway.

This work should be prioritised within NHS England's ongoing review into the use of incentives and levers.⁴⁴

Recommendation: NHS England should improve the QOF end of life care indicators to ensure a greater focus on quality. For example, indicators could include the number of patients with an advance care plan and preferences recorded on an electronic palliative care register.

Urgent attention should be given to updating the QOF end of life indicators. The current indicators for end of life only require participating GPs to maintain a palliative care register and hold three-monthly multi-disciplinary case review meetings to discuss the people on the register.

It was widely felt that these indicators do not reflect best practice. For instance, professionals are not required to carry out an assessment of their patients' needs and preferences. Nor are they required to share the information on the register.

The indicators could be changed to focus on ensuring patient's needs are assessed, an advance care plan is put in place and their end of life preferences are recorded on an electronic palliative care register and shared with other professionals.

Macmillan Specialist Care at Home Service

At a local level, health and social care commissioners have a crucial role in improving choice and ensuring quality of care at the end of life. They should be looking to adopt innovative models of care which are designed around the needs of the people who use them, such as the Macmillan Specialist Care at Home model.

The Macmillan Specialist Care at Home service is an innovative end of life care model, learning from the Motala model in Sweden.

An evaluation of the service in Midhurst has shown it to be a best practice model for end of life care. It delivers high quality experiences for patients and carers. More patients are able to be cared for in their preferred place, with significantly more able to die at home.⁴⁵

The principles of the service are early referral, home-based clinical intervention and close and flexible collaboration between primary care and other community based services.

The service evaluation shows a significant reduction in the numbers of emergency admissions and inpatient stays in the last year of life. This reduced total health-related costs for the last year of life, saving approximately 20% compared to a traditional model.

Increased accountability

Recommendation: The NHS Constitution should be amended to include a right for patients to express a preference about where they are cared for at the end of life, and for that preference to be recorded and shared with professionals involved in their care.

To achieve the changes that are necessary to improve choice at the end of life, it is paramount that the NHS and local authorities are held to account.

The starting point must be the NHS Constitution. However, currently, the Constitution does not set out what people approaching the end of life should expect with regard to choosing where they are cared for and die.

The Constitution should be amended so that, at a minimum, patients have:

- the right to express a preference about where they are cared for at the end of life
- the right to expect that their preference will be recorded and shared (with appropriate consent) with the professionals involved in their care.

The Constitution should also set out a clear pledge that the NHS will work with social care services to meet people's end of life preferences.

Recommendation: The CCG Outcomes Indicator Set and the Adult Social Care Outcomes Framework should include measures on death in the preferred place of care.

Currently, where people live has a significant bearing on where they are able to die. For instance, in Waltham Forest in 2011, only 16% of people who died of cancer died at home. In Corby, the figure was 49%.⁴⁶

Measures on death in the preferred place of care should be added to the CCG Outcomes Indicator Set and the Adult Social Care Outcomes Framework. This will hold CCGs and local authorities to account in a clear and transparent way.

4 Improving patient experience at the end of life

Delivering choice should always be about giving people the support to have a 'good death', no matter where they wish to die. Therefore, understanding experiences of care at the end of life is key to delivering meaningful choice.

As a first step, there is a pressing need to explore how the experiences of people at the end of life can be captured and used to monitor and improve outcomes. Although the VOICES survey of bereaved relatives is an extremely valuable source of information, the lack of nationally collected feedback from people at the end of life needs to be addressed.

Macmillan hopes to carry out more work over the next year to better understand how the experiences of people at the end of life can be measured and improved. We look forward to working with those involved in end of life care in England to achieve this.

5 Conclusion: A 'national choice offer'?

There is urgent need for action to make genuine choice a reality for people at the end of life. However, as this report has outlined, there is much that needs to be done before a 'national choice offer' can be realised.

To make this happen, it is crucial that there is a concerted effort to address all the barriers that prevent people from having a 'good death' in their preferred place.

Crucially, to make a 'national choice offer' happen, action is needed at a national level. By implementing the recommendations in this report, we believe that significant progress can be made towards this ambition.

6 Summary of recommendations

1. The Department of Health and NHS England should make a renewed commitment to the national implementation of EPaCCS and produce a clear strategy and timeframe for achieving this.

NHS England should prioritise investment for national roll-out within plans for the Integration Transformation Fund.
2. The Department of Health should make training in end of life care a priority within the Mandate to Health Education England.
3. Everyone approaching the end of life should have a named professional who is responsible for their care and ensuring, where possible, end of life care preferences are met.
4. Through the Seven Day Services Forum, NHS England should explicitly address the provision of 24/7 services in the community (such as community nursing) that are vital to supporting choice at the end of life.
5. The Government should commit to implementing free social care for people at the end of life by the end of the current Parliament.
6. The Care Bill should make clear that there should be a joint responsibility on health services and local authorities for identifying and signposting carers to information, advice and support.
7. NHS England should explore with stakeholders how national incentives for end of life care can be aligned and clearly encourage improved outcomes for patients, such as being cared for in their preferred place.
8. NHS England should improve the QOF end of life care indicators to ensure a greater focus on quality. For example, indicators could include the number of patients with an advance care plan and preferences recorded on an electronic palliative care register.
9. The NHS Constitution should be amended to include a right for patients to express a preference about where they are cared for at the end of life, and for that preference to be recorded and shared with professionals involved in their care.
10. The CCG Outcomes Indicator Set and the Adult Social Care Outcomes Framework should include measures on death in the preferred place of care.

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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**

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