

# Macmillan Cancer Support

## Response to the Care and Support White Paper/draft Care and Support Bill

October 2012

*Macmillan's ambition is to reach and improve the lives of everyone living with cancer and to inspire millions of others to do the same. We improve the lives of people affected by cancer, by providing practical, medical, emotional and financial support and we push for better cancer care.*



### Executive Summary

Macmillan Cancer Support welcomes the Government's Care and Support White Paper and draft Bill, in particular the emphasis put on social care at the end of life.

Our response to the Care and Support White Paper and draft Bill includes two main sections:

1. Social care at the end of life;
2. Other social care issues which are important to people with cancer and their carers.

Social care at the end of life is our key priority for the social care reforms, and we will be engaging with the draft Bill process on this issue. The opportunity of the draft Care and Support Bill should not be missed in highlighting the importance of social care for people at the end of life.

Our key recommendations on social care at the end of life are:

- The Government should commit to implementing free social care for people on an end of life care register before the end of this Parliament. We believe that this would give more people the opportunity to die in the place of their choice, which, for the majority of cancer patients, is in their own home;
- EPaCCS (Electronic Palliative Care Coordination Systems) should be implemented across the country, and must involve social care as a key partner. Their implementation should be incentivised through using EPaCCS as the data source for an indicator on preferred place of death in the Commissioning Outcomes Framework;
- The 2014/15 ASCOF (Adult Social Care Outcomes Framework) should contain an indicator on choice at the end of life;
- Updated intermediate care guidance should highlight the important role that intermediate care services can play in supporting people at the end of life.

In the second part of our response, we outline our support for the Government's commitment to personalisation and the principle that social care must support someone's well-being, and our broad support for the provisions in the draft Bill. This section also looks at some areas that could be strengthened in the draft Bill:

- The inclusion of independent advocacy in the general duty on local authorities to provide information and advice, as well as facilitating access to these services;
- The inclusion of integration at the point of hospital discharge and re-ablement services, to ensure better joint working between health and social care services;

- Stronger provisions around prevention and early intervention, including the provision of information, advice and advocacy;
- The carer’s needs assessment to include an assessment of the outcomes the carer would like to achieve, and not take into account the carer’s financial resource, as is the case for an adult’s needs assessment.

## **Section 1: Social care at the end of life<sup>1</sup>**

### **Introduction**

***“When push came to shove, Monica should have been allowed to die at home – in her bedroom – as she wished. No-one talked to us about her choices in her last weeks of life, and we weren’t told about the support that we might have been able to get to make her wish of dying at home a reality” – Malcolm, Cancer Voice***

Macmillan Cancer Support strongly believes that people with cancer should have the choice to die at home, surrounded by their friends and family. Yet, too many people continue to die in hospital, against their wishes and at additional cost to the NHS.

We know that social care is vital for allowing people to be cared for in their own homes at the end of life. That is why we, along with the National Council for Palliative Care, Help the Hospices, Marie Curie, the MND Association and Sue Ryder, have been campaigning for people on an end of life care register to have access to free social care.

We are very pleased that the Government stated in the Care and Support White Paper that it sees ‘much merit’ in providing free health and social care in a fully integrated service at the end of life. We also welcome the Government’s commitment to assessing free social care at the end of life through the Palliative Care Funding Review (PCFR) pilots.

In this section of our response we will:

- Reiterate the case for free social care at the end of life to support people to die in their place of choice and explore how we can support the Government’s work to assess free social care at the end of life;
- Suggest how the draft Care and Support Bill can reflect the importance of social care at the end of life;
- Propose interim measures that can be implemented to support people at the end of life to die at home if they wish to do so.

### **The case for free social care at the end of life**

#### **i) What is social care for people at the end of life and why is it so important for people with cancer, their friends, families and carers?**

For Macmillan, social care at the end of life covers non-clinical interventions which greatly enhance a person’s quality of life, and, crucially, ensure people are able to be cared for and die in their own homes. In July 2010 The National End of Life Care Programme published a

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<sup>1</sup> This part of our response will respond specifically to the section in the Care and Support White Paper on ‘Care and support at the end of life’, p. 61.

framework emphasising the central role of social care in end of life care.<sup>2</sup> We hear that it is support with seemingly simple things that can make such a big difference. Interventions can include:

- help with washing, cleaning teeth and dressing;
- turning the patient in bed to prevent sores, and help with going to the toilet;
- preparing meals and small tasks around the home, such as feeding pets.

#### **Case Study – Alison, Cancer Voice**

*“It was quite exhausting, both mentally and physically, to look after my Dad at the end of his life. We had a social care package in place at the very end of Dad’s life to help him with washing and changing. This support helped him to preserve his dignity and, for me, it took away a little bit of the worry. It gave me a break from the situation and also helped me get back to work for a short time.”*

#### **ii) How is the current situation letting people down and why is action needed?**

We only get one chance to get care right for people at the end of life. Removing the social care means-test for people on an end of life care register would eliminate a significant barrier to accessing the social care support they need and lift a stressful financial burden from families.

Macmillan knows that with the right support 73% of people with cancer would prefer to die at home,<sup>3</sup> but currently only 27% are able to do so.<sup>4</sup> As described above, social care support is a vital component of the care people need to allow them to be cared for and die at home if they so choose.

Yet, people with assets above just £14,250 have to make some contribution to the cost of their care and those with assets above the means-test threshold of only £23,250 are required to pay for all of their social care. Anecdotal evidence from social care professionals suggests that people are choosing not to apply for – or indeed refuse – the social care support they need because they cannot afford it or are worried about the lasting impact on their families’ finances. We strongly believe that people approaching the end of life and their families should not have to face this financial burden and concern, nor should be forced to go without the care that they desperately require.

#### **Case Study – Kath, Macmillan Professional**

*“As a Macmillan Specialist Social Worker, I help people nearing the end of life to be discharged from hospital so that they can die at home surrounded by their loved ones. Unfortunately, I’ve seen lots of patients and families refusing the vital social care support they need at home when they find out that they have to pay for it.*

*This means that families are left to cope alone at an extremely difficult time, which can leave them emotionally and physically exhausted. This strain can have a long-lasting impact on families. Sadly it can also lead to people being admitted to hospital right at the end of life when, with the correct care package in place, they could have stayed at home.”*

<sup>2</sup> National End of Life Care Programme (July 2010): *Supporting people to live and die well: a framework for social care at the end of life.*

<sup>3</sup> Macmillan (Feb 2010): Online survey of 1,019 people living with cancer.

<sup>4</sup> Office for National Statistics (2010): Mortality statistics.

In addition, we know that the process for applying for and accessing social care is complicated, intrusive and burdensome at an already extremely stressful, upsetting time.

**Case Study – Sara, Support & Outreach Worker, The Carers Centre**

*“The stress of the means-test for social care can be very frustrating for people who feel that the time they have left with their loved one is running out. They just want to make the most of whatever time they do have and not waste it filling out forms and chasing different services. Paying for social care at the end of life can also cause big financial implications for families as they want the best for their loved one but may not actually be able to fund the care they need.”*

The independent PCFR<sup>5</sup> and the National Audit Office<sup>6</sup> both highlight that the process for accessing state-funded social care is made more complicated still by being carried out independently of the healthcare system. For people who may have only weeks to live, this fragmentation between care systems can not only be distressing, but can lead to delays that can prevent them from having a good death in the place of their choosing.

Another example of a lack of integration is when people at the end of life get caught up in arguments about who will pay for their care. There are two potential funding streams for care at the end of life: the NHS (via NHS Continuing Healthcare – which may provide some social care support) and local authorities. Disagreements about who is responsible for funding a person’s care can arise. This results in delays and patients dying in hospital against their wishes.

Indeed, a recent Macmillan survey showed that 97% of the professionals questioned thought that a lack of financial integration between health and social care was a significant barrier to people receiving the social care support they need at the end of life.<sup>7</sup>

**Case Study – Jan, Macmillan Social Care Coordinator, Northamptonshire**

*“The social care means-test delays people getting the social care they need. In my patch it can take two weeks to decide if the NHS (via NHS Continuing Care) or local authority should fund a person’s social care and then even more time for the care package to be delivered. This delay results in people dying in hospital unnecessarily. We need to get end of life care right first time, there’s no second chance. The people left behind will always remember the circumstances surrounding a death and they are the ones who have to live with their experiences.”*

The PCFR also reports that people may not be getting the care they need because guidelines for fast-track NHS Continuing Healthcare – which is primarily used for people at the end of life – are interpreted differently across the country and are therefore a key cause of inequalities in the care people receive.<sup>8</sup>

All these barriers result in people not getting the social care support they need, which can have a significant impact both on them and their families. We know carer breakdown is often the result of a lack of social care support in the community and a whole systems study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% of

<sup>5</sup> Palliative Care Funding Review (July 2011): *Funding the Right Care and Support for Everyone. Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review.*

<sup>6</sup> National Audit Office (2008): *End of Life Care.*

<sup>7</sup> Macmillan Cancer Support/ICM online survey of 150 health professionals (GPs, Oncologists, Cancer Clinical Nurse Specialists). Fieldwork conducted August 2012. Survey results are unweighted.

<sup>8</sup> Supra note 5.

those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.<sup>9</sup>

**Case Study - Alex, Cancer Voice:**

*“Dorothy was in hospital for six weeks at the end of 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.”*

**iii) Why is implementing free social care at the end of life vital for the NHS?**

The NHS is facing the challenge of making £15-20 billion in efficiency savings by 2015. We believe that implementing free social care at the end of life would not only benefit people at the end of life and their families, but would also represent an important contribution to the Quality, Innovation, Productivity and Prevention (QIPP) agenda. Indeed, in a recent survey of professionals carried out by Macmillan, 86% of respondents agreed that providing people with free social care at the end of life would save the NHS money.<sup>10</sup>

It is vital that we take action now to ensure that more people have their end of life choices respected. The PCFR estimated that, by 2031, 510,496 people will die each year – compared to 461,016 people who died in 2010.<sup>11</sup> There is a pressing need to act now if our health and social care systems are to cope with the challenge of demographic change and the corresponding pressure on services.

Removing the social care means-test, and ensuring access to social care, as part of a coordinated package of care in the community, has the potential to save the NHS money by reducing preventable bed days through:

1. Supporting swifter discharge from hospital;
2. Reducing preventable emergency readmissions.

Removing the social care means-test has the potential to facilitate swifter discharge from hospital, by reducing the complexity of the system and eliminating a key barrier to people going home. We know that helping people to leave hospital sooner can save money. For example, support at the point of discharge for 228 patients in 2009/10 by a Macmillan Social Care Coordinator in Northamptonshire resulted in 326 bed days saved through reductions in delayed discharge and also 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.<sup>12</sup>

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<sup>9</sup> Princess Royal Trust for Carers and Crossroads Care (2011): *Supporting carers: the case for change*, p. 8.

<sup>10</sup> Supra note 7.

<sup>11</sup> Supra note 5.

<sup>12</sup> OPM (2012): *Economic and quality case study: Macmillan Social Care Coordinator – Northampton General Hospital*.

Of people who die in hospital, 89% do so following an emergency admission.<sup>13</sup> Recent research by the Nuffield Trust has shown that access to social care support has the potential to reduce the need for admissions to hospital at the end of life.<sup>14</sup>

When looking specifically at the last episode of care in a person's life, the latest figures published by the National End of Life Care Programme show that there is an estimated potential net saving of £958 per person who dies in the community rather than in hospital. In addition, it estimates that just a 10% reduction in the number of hospital admissions ending in death in England could potentially result in a saving of £52 million.<sup>15</sup>

#### **Case Study: RISE**

*The Rapid Intervention Service for End of Life Care (RISE) set up in NHS Oxfordshire by Allied Healthcare provides rapid health and social care interventions in people's homes to prevent them being admitted to hospital at the end of life. Patients are referred to the service at a point of crisis. This means that they are on the verge of being admitted to hospital, often because the patient is deteriorating rapidly or the family members can no longer cope. However, with support from RISE, 80% of the patients referred to the service in 2011/12 were prevented from having to go into hospital. In 2011/12 the service prevented 287 hospital admissions, costed at £2000 per admission, saving the NHS approximately £200,400.*

Finally, the Nuffield Trust also found that, while hospital costs spike dramatically in the last months of life, social care costs are much more constant. The think tank points out that: 'The marginal costs of increases in local authority-funded social care in the last few months of life appear to be relatively modest, which should allay fears over any costs associated with an entitlement to free social care at the end of life.'<sup>16</sup>

#### **iv) Progress towards free social care at the end of life**

The PCFR, which reported in July 2011, recommended that once a patient is 'put on the end of life locality register, all health and social care should be funded by the state and free at the point of delivery'. This call was supported by the Commission on Funding of Care and Support.<sup>17</sup>

The Government's Care and Support White Paper, acknowledged there is 'much merit' in the principle of free social care at the end of life and committed to assessing free social care at the end of life through the PCFR pilots.

The call for free social care at the end of life is supported by Macmillan and our charity partners – NCPC, Help the Hospices, Marie Curie, the MND Association and Sue Ryder – as well as by the Care and Support Alliance, a consortium of over 50 organisations that represent and support older and disabled people and their carers.

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<sup>13</sup> National End of Life Care Programme & National End of Life Care Intelligence Network (2012): *What do we know now that we didn't know a year ago?*

<sup>14</sup> Nuffield Trust (2012): *Understanding patterns of health and social care at the end of life.*

<sup>15</sup> Supra note 13.

<sup>16</sup> Supra note 14.

<sup>17</sup> Commission on Funding of Care and Support (July 2011): *Fairer Care Funding. The Report of the Commission on Funding of Care and Support.*

In addition, 7862 of our supporters have signed up to an open letter (see appendix), supporting free social care for people at the end of life.

**v) Next steps: working with the Government to assess free social care at the end of life**

Macmillan is pleased that the Department of Health appears keen to work in partnership with us to support the PCFR pilots to assess the benefits of free social care. We feel that we can make a particular contribution by adding the voice of people affected by cancer to the Government's work on this issue, and to conduct research where there are gaps in the Government's own analysis. We hope this work will be taken forward quickly and in the right way to fully analyse the benefits of this policy.

**How the draft Care and Support Bill can reflect the importance of social care at the end of life**

We believe that the opportunity provided by the draft Care and Support Bill to cement the importance of social care in end of life care should not be missed. Given this, we are surprised there is no explicit mention of end of life care in the main body of the draft Bill.

Reference could be made to end of life care in, for example, Clause 1, to strengthen the definition of well-being, in Clause 6, to highlight the importance of integrated care for those at the end of life, and in Clause 24, to stress that preferences for end of life care should be included in care and support plans.

We would also like assurances that the draft Bill will continue to pose no legal challenge to the implementation of free social care at the end of life.

**Interim measures**

We welcome the recognition in the Care and Support White Paper that, since the PCFR pilots will not report for two years, there is the need to implement interim measures to improve support for people at the end of life. The White Paper specifically referenced the implementation of EPaCCS (Electronic Palliative Care Coordination Systems) and updating current intermediate care guidance. We discuss here how the Adult Social Care Outcomes Framework (ASCOF) can also incentivise improved end of life care.

**i) EPaCCS**

EPaCCS, previously known as 'locality registers', hold key information about an individual's preferences for care at the end of life, which can be accessed by a range of services providing that person's care.

These registers encourage the identification of patients who are at the end of life and conversations with them about their care wishes. They also support better communication and coordination, which is likely to reduce preventable bed days, and ultimately ensure a greater proportion of people are able to die in their preferred place of care with their preferred care package.

The benefits of EPaCCs are already being realised. For example, in South Essex PCT, of those people who were on the register and stated where they wanted to be cared for at the end of life,

70% died in the place of their choice. Overall, of those people on the register who died, 18% died in hospital, whereas 46% died at home.<sup>18</sup>

We are very supportive of the work the Department of Health and the National End of Life Care Programme (NEoLCP) are leading to support the implementation of EPaCCS across the country. However, we are concerned about the lack of involvement of social care in EPaCCS. We think it should be a priority for the Department of Health and the NEoLCP to ensure social care needs are included and recorded as part of EPaCCs to acknowledge the vital role social care plays in end of life care.

We also firmly support the PCFR's recommendation that every Clinical Commissioning Group should hold an end of life locality register. We think that the implementation of EPaCCS can be incentivised by:

- The inclusion of an indicator in the Commissioning Outcomes Framework (COF) on preferred place of death, for which EPaCCS should be the data source;
- Updating the current QOF indicators (which incentivise GPs to: i) hold a list of their patients who are at the end of life and ii) to have regular meetings to discuss these patients) to incentivise GPs to lead the implementation of EPaCCS in their area.

## **ii) Intermediate care**

We know that services that are classified as 'intermediate care' can be appropriate for supporting people at the end of life. For example, in Torbay the care trust's intermediate care team has had its remit widened to include people at the end of life. In these cases, rather than focusing on outcomes for the long term, they focus on improving patients' quality of life in the community for as long as possible.

While in Central and Eastern Cheshire, the majority of patients that the 'hospital at home' service supports are at end of life. This service provides a short period of intensive support in the person's home. Trained professionals will visit the person up to four times a day and will aim to meet not only their medical needs, but also their personal care needs.

However, we also know that the current understanding around and provision of intermediate care services is patchy. In some areas, intermediate care will be used to support people to leave hospital swiftly and remain in their homes, whereas in other places it will not.

We therefore think that updated intermediate care guidance should:

- Set out a clear definition of 'intermediate care';
- Highlight the important role that intermediate care services can play in supporting people at the end of life by including specific outcomes that are relevant for people at the end of life, such as: supporting people to die at home if they so choose; maximising quality of life; and supporting carers, to help encourage a shift in the way in which intermediate care is viewed;
- Encourage a broader awareness of the importance of service planning to support people at the end of life. Local areas should have clear local plans for reducing emergency

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<sup>18</sup> Department of Health (October 2012): *End of Life Care Strategy: Fourth Annual Report*.



readmissions and supporting swifter discharge for people at end of life: it should be clear which service is going to provide this support in each area.

### **iii) Adult Social Care Outcomes Framework (ASCOF)**

The Adult Social Care Outcomes Framework includes various indicators which will 'give an indication of the strengths of social care and success [of local authorities] in delivering better outcomes for people who use services.'<sup>19</sup> We believe that the omission of end of life care from the current set of indicators is a missed opportunity, both in terms of ensuring that end of life is a priority for local authorities and in supporting the Government's ambition to align the various health and social care outcomes frameworks.

We are pleased to have already engaged with officials working on the ASCOF and understand that the 2013/14 iteration will be published before the end of the year. We would like to see:

- A clear commitment in the 2013/14 ASCOF to the development of an indicator on choice at the end of life;
- Inclusion of an indicator on choice at the end of life in the 2014/15 ASCOF.

## **Section 2: Other social care issues**

This part of our response focuses on other social care issues (besides social care at the end of life) of importance to people with cancer and their carers. Specifically, we focus on the following themes:

- Integration;
- Prevention and early intervention;
- Information, advice and advocacy;
- Carers.

We support the inclusion of legislative provision on all of the above issues, but have highlighted where we believe the provisions could be strengthened and enhanced to support the needs of people with cancer and their carers. In particular, we consider that Clause 2 (on information and advice), Clauses 6-7 (on promoting integration and preventing needs) and Clause 10 (on assessment of a carer's needs for support) need to be strengthened.

### **Introduction**

Macmillan welcomes the Government's commitment to personalisation in the *Care and Support White Paper*, and strongly supports the principle underpinning the draft *Care and Support Bill* that social care must support someone's well being. We broadly welcome these clauses in the draft Bill.

We strongly support the need for greater independence, choice and control over care through enabling people affected by cancer to have a meaningful voice in the care that they receive, ensuring their dignity is upheld at all times. However, this is not yet a reality for people with cancer and their carers.

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<sup>19</sup> Department of Health (March 2012): *Transparency in outcomes: a framework for quality in adult social care. The 2012/13 Adult Social Care Outcomes Framework.*

People living with cancer tell us that their experience of accessing health and social care services is ‘confusing’, ‘scary’ and ‘lonely’, resulting in them ‘feeling isolated and powerless’. Crucially, they do not know where to go to get support for their social care needs and consequently their needs are not being met. Carers of people with cancer share these difficulties in accessing and understanding what social care support is available for the people they care for. The vast majority of carers of people with cancer (95%) have not had an assessment of their needs.<sup>20</sup>

These experiences are even more common for socially excluded communities as they are already disadvantaged within society. They repeatedly tell us that this makes it harder for them to participate meaningfully in decision making about their care and access services that enable them to achieve the same benefits as other groups.

In light of the problems associated with a lack of joined up working between health and social care, we were surprised that the White Paper and draft Bill did not include stronger links with the NHS.

### **Integration**

We welcome measures to improve integration between health and social care, and the principle that integration is about the individual, their needs and their outcomes. In particular, we strongly support the White Paper’s commitment to new payment mechanisms to reduce delays in hospital discharge, and to aligning the NHS, public health and adult social care Outcomes Frameworks.

We welcome provisions in the draft Bill for co-operation between local authorities and the NHS in meeting the care and support needs of adults and carers, although other health partners should be referenced, particularly GPs. We also strongly support the new duty on local authorities to promote integration between health and social care services. However, we are concerned that there is no detail about integration at the point of hospital discharge.

People with cancer are not receiving their health and social care in a joined up way. They have difficulty navigating both the health and social care system and knowing what social care services and support is available to them. At the end of treatment, people with cancer are left feeling alone and isolated, not knowing where to go to get help for their non-medical needs. Over a quarter of people with cancer (26%) say they feel abandoned by the system when they are not in hospital.<sup>21</sup> As a result, people with cancer are not being identified as potentially needing social care support and are not being referred to social care for assessment.

Therefore, **we recommend that Clause 6 of the Bill is strengthened to include integration at the point of hospital discharge.** We support the Care and Support Alliance’s call for a requirement on local authorities to this effect. Namely, that everyone who has a care and support need (regardless of the reason for their admittance in the first place) is assessed at the point of discharge from hospital.

We recognise the importance of allowing for innovation in different models of integrated care locally. However, there must be guidance for local authorities on how to exercise their new duty on integration if the social care needs of people with cancer are to be identified at an early stage.

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<sup>20</sup> Macmillan Cancer Support (2011): *More than a million. Understanding the UK’s carers of people with cancer.*

<sup>21</sup> Macmillan Cancer Support (2008): *Social care for cancer.*

This guidance should include detail on the roles of health and wellbeing boards, joint strategic needs assessments and health and wellbeing strategies.

Re-ablement and intermediate care services are important in the transition from health to social care. **We recommend that the Bill is strengthened to include and define re-ablement and intermediate care services.** As suggested by the Care and Support Alliance, local authorities must consider arranging or delivering re-ablement and intermediate care services where this will benefit the adult or carer's short-term care and support needs.

Health and social care professionals play a vital role in improving and promoting better joined up care, and we were disappointed that this was not reflected in the White Paper. **We would urge the Government to consider measures to encourage the health and social care workforce to work across organisational boundaries, understand each other's functions and work together on workforce planning.**

### **Prevention and early intervention**

We welcome the duty on local authorities to incorporate prevention and early intervention into commissioning and planning, and the need for local authorities to identify unmet social care needs in their area. However, we are concerned that the prevention clause in the draft Bill makes no reference to the provision of information, advice and advocacy services (even though the White Paper recognises the vital role of information and advice in reducing the risk of people reaching crisis point). The prevention clause also makes no reference to managing the care and support needs of carers.

For many people living with cancer, prevention is about making sure they are supported in the community, following their treatment, to help with their recovery and rehabilitation. However, people with cancer are not routinely being identified as potentially needing social care support and so are not being referred to social care for assessment. Even if they do receive an assessment, those with low or moderate needs are not receiving the support that they need.

Prevention and early intervention is also about ensuring that carers' needs are identified and that they have the support they need to continue in their caring role, and to live their own life alongside this.

Information, advice and advocacy are vital to identifying care and support needs of people with cancer and their carers at an early stage (including those at risk of developing support needs) and ensuring the right support is provided to prevent, reduce or delay these needs.

**We recommend that Clause 7 of the Bill is amended to include the provision of information, advice and advocacy, and support for carers.**

As a member of the Care and Support Alliance, we support the view that the draft provision on charging is counter-productive when we need a shift away from providing crisis care towards universally available forms of prevention.

### **Information, advice and advocacy**

We welcome the general duty on local authorities to provide information and advice services to everyone, and the right for people who have had an assessment but do not meet the eligibility

criteria to access information and advice about their needs. Whilst we welcome the recognition in the White Paper of the vital role of advocacy, we are concerned that the draft Bill contains no requirements for local authorities to make advocacy services available.

People with cancer need information and advice from health and social care professionals to help them understand their needs and the support available to them. Carers also need information and advice to help them in their caring role, but they regularly miss out on assessments because they don't identify themselves as carers.

However, information and advice is not sufficient to enable participation in decisions about care. Independent advocacy should also be available as this helps to secure rights, choice and control - ultimately ensuring that people affected by cancer, and those with other long-term conditions, can participate in key decisions about their life and treatment. This is particularly important for disadvantaged groups who are most in need of advocacy support and those at risk of social isolation, who may require more encouragement to participate in decision-making about their care.

Macmillan believes that advocacy should be broadly defined and should include taking action to give people a voice in decisions relating to their care, represent their interests and ensure that these are met. This will help them obtain the services that they need.

**We recommend that Clause 2 of the Bill, which outlines the duty on local authorities to provide information and advice, is amended to include independent advocacy and 'facilitating access' to services.** Local authorities should provide access to advocacy, as well as information and advice, to people without eligible needs. It is vital that such services are independent (of local authorities and policy-makers) to ensure that they are a trusted form of support.

Advocacy services are needed throughout the care pathway of people with long-term conditions, particularly in instances of re-assessment, review and complaints, as opposed to only at assessment. We would like to see a stronger commitment to independent advocacy throughout the Bill.

As part of the implementation of the White Paper, we would like to work with the Government in defining users of advocacy services, and discuss the work we are doing to provide advocacy support to people affected by cancer from particularly vulnerable groups.

## **Carers**

We welcome the new rights for carers to assessments and services, and their involvement in how the needs of the person they are caring for are being met. We also welcome the removal of the requirement for carers to be providing 'regular and substantial care' to qualify for support. However, we would like the Bill to go further in placing carers and adults on the same legal footing, particularly in relation to the assessment of need.

Over 1 million people in the UK are caring for someone with cancer and half of them are missing out on the support available to them.<sup>22</sup> The support carers provide at all stages of the cancer pathway is vital, whether that is helping with shopping, dressing or taking people with cancer to

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<sup>22</sup> Supra note 20.

the hospital, or the emotional support they provide. Cancer, like other conditions, can be fluctuating so care may not be given regularly but as and when required.

Macmillan research shows that 95% of carers of people with cancer have not received an assessment of their needs.<sup>23</sup> We therefore strongly support measures outlined in the White Paper to require the NHS Commissioning Board and Clinical Commissioning Groups to work with local authorities and local carers organisations to ensure that carers are identified and supported. This support must include the provision of information - including signposting carers to local authorities for assessment of their needs.

Legally, it is important that carers have rights equal to those they care for. The draft Bill goes a long way to achieving this, however the assessment of a carer's need for support does not include an assessment of the outcomes that the carer wishes to achieve in day-to-day life (whereas the adult's assessment does). We believe that all the outcomes the carer wishes to achieve should be considered. In addition, the duty to carry out the carer's assessment does not apply regardless of the carer's financial resources (in contrast to the adult's assessment).

**We recommend that Clause 10 of the Bill is amended so that the duty of local authorities to undertake a carer's assessment includes an assessment of all the outcomes the carer wishes to achieve and should apply regardless of the carer's financial resources.**

We would also like to see the anomaly removed whereby young carers still have to request an assessment (or their parents have to on their behalf), while adult carers no longer have to request a carer's assessment.

### **Eligibility and funding**

As a member of the Care and Support Alliance, we believe that the Government must urgently set out a clear timetable for reforming social care funding. Without this, the vision outlined in the White Paper will be difficult to achieve.

We welcome the proposal for a national eligibility threshold but we would want to see the Bill clearly define any minimum entitlement to care and support. If the level is set at 'substantial' we would want assurance that people with 'low' or 'moderate' needs will be supported, including signposting to other services that can help meet their needs.

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<sup>23</sup> Supra note 20.

## Appendix

### Open letter supporting free social care at the end of life

According to research by Macmillan Cancer Support, the majority of cancer patients would prefer to die at home, surrounded by their loved ones. However, at present only 27% of people do so. Not only is a home death what most people want, there is also growing evidence that this saves money for the NHS compared with a death in hospital.

As campaigners for Macmillan Cancer Support, we are pleased to see that the Westminster government's recent Care and Support White Paper recognised that there is 'much merit' in providing free social care to patients at the end of life. The commitment given to assessing this policy is very welcome and is a significant step towards improving end of life care.

It is vital that free social care at the end of life remains a priority as reforms to the social care system progress. We ask the government to work closely with Macmillan as this proposal is assessed over the next two years. In the meantime it's really important that the government acts as a matter of urgency on its promise to improve the experiences of people who are currently nearing the end of life and require support to die in the place of their choosing.

Yours faithfully,  
Macmillan Cancer Support campaigners