

Macmillan Cancer Support

Response to the Care and Support Green Paper

November 2009

Executive Summary

- There are over 1.6 million people in England living with a cancer diagnosis¹. It is a cause for celebration that, due to advances in detection and treatment, more people are now receiving high-quality cancer treatment within the NHS and surviving following a cancer diagnosis. However, although cancer treatments are becoming more effective, patients and carers are not receiving the supportive care services they need.
- Macmillan knows that many people living with cancer and their carers need access to appropriate practical support services (such as help with housework or childcare), emotional and psychosocial support services (such as counselling), financial information and advice, and other information and support services.
- We broadly support the Government's vision for the future of care and support, particularly in its ambition to end the 'postcode lottery' of care and raise the quality of services, however we have some specific concerns about the proposals.
- Many people living with cancer are currently not being referred to social care for assessment and struggle to obtain services. Even if people do receive an assessment, due to the current level of social care resourcing, those with low or moderate needs are not receiving the support that they need. We are concerned that the Green Paper does not address these issues, and that under the new proposals there would not be adequate support for people with low or moderate social care needs to prevent conditions escalating.

Key recommendations

- We strongly oppose the proposal to use current disability benefit funding streams, such as Attendance Allowance, to make up the shortfall in social care funding. These are important benefits for people living with cancer that help them meet the extra cost of their disability, such as a special diet or travelling to hospital, not just to pay care costs.
- There should be more emphasis in further plans for the future of social care on investment in services for people with low or moderate needs. Supporting people living with cancer in the community who have low or moderate social care needs can help them to manage their own conditions, potentially preventing emergency admissions to hospital if conditions escalate.
- The Government should be more specific about plans to encourage joint working between health and social care, including alignment of priorities and targets, to ensure that all the needs of cancer patients are considered and supported, not just their clinical needs.
- Under a new system, everyone living with cancer should automatically have a holistic assessment of their needs, including their social care needs, at key points in the cancer journey.

¹ King's College London, Macmillan Cancer Support and National Cancer Intelligence Network (2008). *Cancer Prevalence in the UK, 2008*

Introduction

1. Macmillan improves the lives of people affected by cancer, providing practical, medical, emotional, psychosocial and financial support. We help people to help themselves, and each other, by signposting to the network of cancer self help and support groups and offering good practice based training and support. We fund services to support practical and emotional needs and provide grants and benefits advice to people living with cancer, and carers. This year we are investing over £33 million in social care and information services. At the end of June 2009, there were 245 Macmillan Information professional posts, 125 Macmillan social work professional posts and 193 Macmillan welfare benefit adviser posts, plus 33 carers schemes, 101 information centres, 94 benefit advice schemes and 9 befriending or bereavement schemes.
2. There are over 1.6 million people in England living with a cancer diagnosis². One in 10 people over the age of 65 have had a cancer diagnosis³. It is a cause for celebration that, due to advances in detection and treatment, more people are now receiving high-quality cancer treatment within the NHS and surviving following a cancer diagnosis, but the effects of cancer do not stop once treatment is over.
3. People affected by cancer have social care needs:
 - a. **Practical needs:** Having cancer and being treated for cancer can leave people feeling tired, weak, in pain, and ill. The frequency of treatment can limit what people can practically do, and surgery can affect people's physical strength and mobility, either temporarily or permanently. They can find it difficult to do household chores like shopping and cooking. Getting around can become more difficult as they have trouble driving or managing stairs. They may also have problems getting up and going to bed, dressing and undressing, and maintaining personal hygiene. Four out of ten people living with cancer (41%) say that the physical effects of their cancer or treatment are difficult to cope with⁴.
 - b. **Emotional and psychosocial needs:** Being told that having cancer is a possibility, and actually having it, is both frightening and distressing for the person with the disease and their family and friends. Nearly half of people with cancer (49%) say they experience depression as a result of their cancer diagnosis⁵, and more than four in ten (45%) say that the emotional aspects of cancer are the most difficult to cope with, compared to physical effects⁶. Studies have shown links between depression and cancer survival; across 26 studies on

² King's College London, Macmillan Cancer Support and National Cancer Intelligence Network (2008). *Cancer Prevalence in the UK, 2008*.

³ Ibid.

⁴ Macmillan Cancer Support (2006). *Worried Sick – the emotional impact of cancer*.

⁵ Ibid.

⁶ Ibid.

people living with cancer and the effects of depression on survival, mortality rates were up to 25% higher in people experiencing depressive symptoms⁷.

- c. **Financial needs:** 91% of households suffer loss of income and/or increased costs as a direct result of cancer⁸. People with cancer can find it hard or impossible to work during their treatment and beyond, because they feel tired, weak, in pain, and ill. They can encounter unexpected expenses, like the increased cost of travel to and from treatment, and hospital car parking charges.
 - d. **Other care needs:** In addition to the effects of cancer and/or treatment, nearly half of all people living with cancer have at least one other long-term condition, and nearly a quarter have at least two⁹.
4. Carers of people living with cancer also have social care needs. Research shows that 38% of cancer carers spend more than 30 hours caring each week, and that over half of cancer carers feel anxious at least some of the time – more than any other type of carer¹⁰. Many long-term carers have to work part-time, miss out on promotions or give up work altogether to care, which has a financial impact on them¹¹.
 5. Not supporting people living with cancer in the community can lead to their conditions escalating, and potentially to inappropriate hospital admissions. As an indication, of the 14,500 cancer patients in hospital at any one time (at a cost of £2.9m per day to the NHS), 60% have been admitted as an emergency¹².
 6. People living with cancer and their carers currently struggle to obtain the services they need to support their social care needs. Cancer is perceived as a ‘health’ issue, rather than a health *and* social care issue, as was highlighted by the comments from the Health Secretary and others during the launch of the Green Paper. Announcing the publication of the Green Paper in Parliament, Andy Burnham said: “*We need a care system that people can rely on, that does not penalise people for their prudence and that ends the cruel lottery of older people facing financial hardship because they happen to get dementia, for example, rather than cancer.*”¹³ In recent research, commissioners confirmed that local authorities tend to view cancer as primarily a health issue and that PCTs traditionally do not see social care as a core service in relation to cancer care¹⁴. The emotional, psychosocial, practical and financial needs of people living with cancer are ‘falling between the gap’ in health and social care services, with neither one taking responsibility for addressing these needs. Over a quarter of people living with cancer (26%) say they feel abandoned by the system

⁷ Jillian R. Satin, Wolfgang Linden, Melanie J. Phillips (2009). *Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis.*

⁸ Macmillan Cancer Support (2006). *Cancer costs – the hidden price of getting treatment.*

⁹ Macmillan Cancer Support (2008). *Health and well-being survey.*

¹⁰ Ibid.

¹¹ Carers UK/Leeds University (2007). *Valuing carers – calculating the value of unpaid care.*

¹² [Ann Driver \(2008\). Overview of Transforming Inpatient Care Programme and the synergy with the NCSI programme.](#)

¹³ HC Deb, 14 July 2009, c157

¹⁴ Macmillan Cancer Support (2008). *Social care for cancer.*

when they are not in hospital¹⁵. Similarly, 24% of people providing care to people living with cancer say they feel abandoned¹⁶.

7. Our research shows that people with cancer are often not referred by health services to social care services for an assessment¹⁷. As an indication, of the 32 people affected by cancer questioned at recent Macmillan Cancer Voices conferences, 25 had not received an assessment of their social care needs¹⁸. It is clear that people living with cancer who are not even assessed for their social care needs in the first place cannot be receiving the support and services they need to help them cope with their condition in the community.
8. Even in cases where people living with cancer do receive assessments, they often still do not access support services, because they are classed as having 'low' or 'moderate' needs (as defined under the Fair Access to Care Services (FACS) criteria). Because social care in England is so under resourced, local authorities focus on people with 'substantial' and 'critical' needs, leaving people with low or moderate needs without the support they need^{19 20}. The Commission for Social Care Inspection found that local authorities also misinterpret FACS criteria to mean that low-level support services do not need to be provided and that complex needs always require complex interventions.²¹ We know from our experience of delivering services that this is not the case, and that low-level support services can be beneficial for people with a range of needs.

The vision for the future

Question 1: We want to build a National Care Service that is fair, simple and affordable. We think that in this new system, there are six things that you should be able to expect: prevention services; national assessment; a joined-up service; information and advice; personalised care and support; and, fair funding

- (a) Is there anything missing from this approach?
- (b) How should this work?

9. Macmillan supports in principle the Government's vision for the future of care and support, however we are disappointed at the apparent lack of attention in the proposals to supporting disabled people of working age as well as older people, and have some concerns as to how the vision might be borne out in practice.
10. The next section looks at the proposals in each of the areas identified by the Government to be expected under a new National Care Service.

¹⁵ Ibid.

¹⁶ Macmillan Cancer Support (2006). *Worried Sick: The emotional impact of cancer*.

¹⁷ Macmillan Cancer Support (2008). *Social care for cancer*.

¹⁸ Macmillan Cancer Voices conferences in London and Bromwich, 2008. Of 32 people questioned, 25 had not received an assessment, 4 had, and 3 did not answer.

¹⁹ Commission for Social Care Inspection (2008). *The state of social care in England 2007-08*.

²⁰ Commission for Social Care Inspection (2008). *Cutting the cake fairly: CSCI review of eligibility criteria for social care*.

²¹ Ibid.

Prevention services

11. The Government's vision for providing comprehensive prevention services is too focussed on supporting older people from developing severe social care needs, and does not give enough detail on supporting disabled people of working age. Prevention is not just about avoiding older people developing severe social care needs; for many people living with cancer, as for those with other long-term conditions, it's about making sure they are supported in the community following their treatment to ensure they are able to manage their conditions.
12. Many people affected by cancer who do receive social care assessments are assessed as having 'low' or 'moderate' needs, and therefore do not qualify for state support. Without sufficient care and support for those needs, however, conditions can escalate, and needs can become 'substantial' or 'critical', resulting in poor outcomes for individuals and placing a significantly larger burden on health and social care services. The new National Care Service must allocate sufficient resource to low-level social care services, as an investment in longer-term, wider societal benefits. We wholeheartedly agree with the Equality and Human Rights Commission's assessment that to succeed in creating a sustainable approach to care and support, we need to "*cultivate a cohesive society which maintains a commitment to pooling risk through a modern active welfare state in a way which is seen to be mutually beneficial*"²².
13. Macmillan supports the principle of re-ablement for people leaving hospital. Over a quarter of people living with cancer (26%) say that they feel abandoned by the system when they leave hospital following treatment. However, we believe re-ablement - helping people to get back some of the skills and confidence they may have lost through a disability or going into hospital - should extend beyond practical and physical help. For example, giving someone living with cancer the right advice and support to return to work following treatment improves the quality of their life, and can help emotional, psychosocial, practical and financial support needs escalating. The wider benefits to society of investing in this support are significant. Economic analysis by Monitor for Macmillan has concluded that a 4-6% increase in the numbers of people getting back to, and staying in, work after cancer would result in an overall net value to the UK economy (saved benefits and income tax paid etc) of £102-£113 million per year.
14. We are pleased that the Government has committed in the Green Paper to making sure that everyone can easily get hold of information about prevention and early intervention. For people living with cancer, this should mean that they get information post-treatment on what to look for as signs of recurrent or progressive illness and what to do should they suspect this, as well as information on emotional, psychological, financial and practical support. The Government should ensure that this commitment is realised for people living with cancer in the delivery of Information Prescriptions, which are due to be rolled out across England next year.

Assessments: joined up and portable

15. Macmillan wholeheartedly supports the proposal for a nationally portable assessment, and the vision that all the services that an individual needs work

²² Equality and Human Rights Commission (2009). *From safety net to springboard*.

together smoothly. We support the creation of an assessment process that considers all of a person's individual needs, means and eligibility in a more joined-up way, and welcome the Green Paper's commitment to reassessment. We believe that everyone with cancer, and their carers, should have a holistic needs assessment at the point of diagnosis, to be repeated as necessary at key points in the cancer journey, including during treatment, post treatment and when preparing for palliative care.

16. However, our research shows that currently many people living with cancer are not referred by health services to social care services for an assessment²³, despite the NICE Supportive and Palliative Care Guidance recommending that '*assessment and discussion of patient's needs for physical, psychological, social, spiritual and financial support should be undertaken at key points*'²⁴. Research by the Commission for Social Care Inspection also suggested a huge shortfall in carers having assessments of need, despite the legal duty on local authorities to provide these²⁵. Carers for people living with cancer are often particularly missed because people living with cancer usually enter the system through the NHS rather than the social care system and there are no legal duties on NHS secondary care providers to identify carers or provide them with information. However good an assessment process is, it will not adequately serve to improve care and support in England if the right people are not identified for assessment in the first place. The provision of holistic assessments for people living with cancer, that take into account social care needs, must be improved. We also recommend the Government introduces a legal duty on NHS bodies to routinely identify and provide information to carers, including signposting them to local authorities for an assessment.
17. We support the principle of a more joined-up assessment process that minimises multiple questioning of the same people for the same information, and welcomed the introduction of the Common Assessment Framework for Adults on that basis.
18. The portability of an assessment should not prevent it being able to be appealed by a patient/carer. People should also be able to ask for a reassessment of their needs at any time.
19. The ability of the health and social care workforce to deliver joined-up assessments for people living with cancer and carers will be crucial. Some local authority commissioners interviewed as part of research we conducted said their staff may not fully understand the needs of people with cancer to be able to assess them effectively²⁶. Assessors need to be skilled in understanding the needs of people with different long-term conditions who may present for an assessment, and assessment guidelines should take the needs of people with different long-term conditions into account. In addition, healthcare professionals must be trained to recognise both the clinical and social care needs of people diagnosed with cancer to ensure that they are referred for assessment in the first place. There may need to be joint workforce planning and more cross-service training to achieve this.

²³ Macmillan Cancer Support (2009). *Social care for cancer*.

²⁴ NICE (2004). *Improving Supportive and Palliative Care for Adults with Cancer*.

²⁵ Commission for Social Care Inspection (2008). *The state of social care in England 2007-08*.

²⁶ Macmillan Cancer Support (2009). *Social care for cancer*.

Information and advice

20. Macmillan supports the vision in the Green Paper that people will be able to find their way through the care and support system easily, and that they will find it easy to get information about who can help, what care they can expect and how quickly they can get it. We know that currently many people living with cancer and carers do not feel they are getting the right information and support. Macmillan's *Worried Sick* report found that fewer than one in five people affected by cancer felt confident about how and where to access social care services. Four in ten also said they wanted information and advice about available health and social care services but around half were not able to get it²⁷.
21. Information and advice should be available to everyone, regardless of their eligibility for state funding. As such, we welcomed the recommendation in *Putting People First* that local authorities should develop local information, advice and advocacy services, however our research suggests that few information services are being planned²⁸. We are encouraged that the Green Paper states a desire to build on the recommendation in *Putting People First*, and we would urge PCT and local authority commissioners to work together with the voluntary sector to realise the Green Paper's vision for information and advice, and ensure that these services are available to everyone.
22. We wholeheartedly agree with the principle in the Green Paper that it should be made easy for health professionals to direct people to the correct information on care and support. We feel strongly that it should not only the people who ask for it, but also those who do not, that are given appropriate information. Tailored Information Prescriptions, which are due to be rolled out in 2010, should, if implemented effectively, provide a simple process through which appropriate, relevant, and high-quality information is delivered by health professionals through face-to-face communication at key points in the cancer journey. We urge Government to give sufficient resource to the delivery of Information Prescriptions as a vital tool in the delivery of information to cancer patients.
23. Local information, advice and advocacy services should work closely with local Information Prescription services, to ensure that people living with cancer are not only directed to relevant and appropriate information sources through their Information Prescriptions, but that they also know what care and support they are entitled to, and what is available in their area.
24. Information should always be evidence based, balanced, regularly updated, composed in plain language, culturally sensitive and available in a variety of formats, to ensure that the improvement in information services helps to tackle inequalities rather than exacerbate them. Improved information services must offer information to support all someone's needs, in a way that is accessible and understandable to them. Currently, this is not always the case: for example, the ONS report, *Focus on social inequalities*, found that 41% of people with additional language needs had no one to help with interpreting when visiting a GP or health centre²⁹, and the 2004 National Cancer Patient Survey showed that only 34% of men with prostate cancer

²⁷ Macmillan Cancer Support (2006). *Worried Sick*.

²⁸ Macmillan Cancer Support (2009). *Social care for cancer*.

²⁹ Office for National Statistics (2004). *Focus on social inequalities*.

reported having been given information on support or self-help groups, compared to 64% of all people living with cancer³⁰.

Personalised care and support

25. Macmillan supports the principle of person-centred care, with care and support designed around an individual's needs. In order for this to become a reality, public services must be joined up and responsive to an individual's needs (see answer to question 2).

Supporting carers

26. We welcome the recognition of the invaluable role of carers in the Green Paper, however we are disappointed that there is not more in the Paper about how a new National Care Service would support carers specifically. Carers must not be seen as a 'free' resource, but instead be properly supported, under a National Care Service. As a recent research report from the Social Policy Research Unit at the University of York highlighted, *'Assumptions about the availability of unpaid informal care at home as a free resource (in contrast to formal domiciliary services or institutional care) will almost certainly under-estimate the additional public expenditure costs that arise from unsupported informal care'*³¹.
27. We are concerned that existing Government commitments to supporting carers are not being fulfilled. The Carers Strategy promised £150m to PCTs to provide breaks for carers over two years; £50m to be given in 2009/10 and £100m in 2010/11. However, under recent Freedom of Information requests to PCTs it was revealed that only 23% of this year's £50m has been used by PCTs to increase services for carers³². We are concerned that because this funding was not ringfenced, or its purpose sufficiently communicated by national Government, it has been used by PCTs for other things. Carers must be properly supported to care, and the Government must make sure that any resources that they commit to supporting carers do not get lost in wider PCT funding. We support the recommendations on funding for carers' breaks made by the Standing Commission on Carers in their report on the progress of the Carers Strategy³³. Firstly, that the Commission, the Department of Health and the NHS should gather evidence of how the new resources have been spent and on the cost-benefits and improved health outcomes of supporting carers in their caring roles, including the provision of breaks. And secondly, that health ministers should accord support for carers a higher status in the next planning round for the NHS Operating Framework (2011/12 onwards).
28. We welcomed the commitments in the Carers Strategy to better enable carers to combine paid employment with their caring role, and have been encouraged by the progress made in some areas, for example, the recruitment of specialist regional Care Partnership Managers to improve information on local carer support for staff and customers. However, we are concerned that not enough has been done to inform carers of their rights to flexible working, as promised in the Strategy. Again, we support the recommendation from the Standing Commission on carers that BIS

³⁰ National Audit Office (2005). *Tackling cancer: improving the patient journey*

³¹ The University of York Social Policy Research Unit (2009). *Care Provision within Families and its Socio-Economic Impact on Care Providers*.

³² The Princess Royal Trust for Carers / Crossroads (2009). *Primary Care Trusts and The Carers Strategy*.

³³ Standing Commission on Carers (2009). *Report of the Standing Commission on Carers 2007 to 2009*.

and GEO should continue to target carers and employers to ensure that the awareness-raising campaign on flexible working has maximum impact.

29. We also want to see more progress made on the commitment to review carers' benefits, and we urge the Department for Work and Pensions to set out its timetable for welfare reform and its plans to review carers' benefits as soon as possible. We are pleased to see that so far £25m of the £38m committed by the Government to supporting carers to work has been spent in this area, but are concerned that the remaining funding may not be used for this purpose, given that, as is the case in other funding streams, it is not ringfenced, and JobCentre Plus will be under pressure to use the funding in different areas in the recession.
30. The Government must ensure that existing commitments to supporting carers are fulfilled, and that future plans for a new National Care Service explicitly set out what provisions there will be under the new system to ensure that carers are properly valued and supported in their caring roles.

Personal budgets

31. Though we welcome the Government's commitment to roll-out personal budgets for people who are eligible for publicly-funded social care and support the principle of enabling people to exercise control over their own lives, we have a number of concerns.
32. People's needs can vary through their cancer journey, due to changes in their disease and/or fluctuating side effects, which will need to be borne in mind when assessing people with cancer for a personal budget. People will need to be able to have a reassessment of need at key points in the cancer journey and be able to refer themselves for an assessment.
33. Not everyone will wish to manage their own budget or have the skills to do so. We welcome the option for people to ask the council to manage their budget for them if they so wish.
34. The introduction of personal budgets will mean people will need access to information, advocacy services or an independent broker to help them understand the choices available to them and subsequently access services that meet their needs. Currently, advocacy services are patchy. We believe that any personal budgets programme needs to be supported by a comprehensive system of support and advocacy, to ensure that there is equality of access and outcome for all receiving these funds.
35. If personal budgets are to give people choice and control over their own care, then there will need to be a range of services available locally that can meet people's needs. Local authorities will need to be responsible for ensuring that people are signposted to high-quality services and that services exist that meet people's full range of needs. For people with cancer and their carers, these needs include access to information, financial advice and support, emotional, psychosocial and practical support as well as end of life care and bereavement services.
36. People who become eligible for continuing care provided by the NHS may lose their entitlement to a personal budget and the choice and control a personal budget allows. The Department of Health needs to ensure that people do not have to choose

between a fully funded yet potentially paternalistic model of healthcare provision and a flexible and personal budget to which they may have to contribute. The Department of Health should consider the effect on people's ability to have choice and control over their care package should they lose their personal budget because they are entitled to continuing care.

Fair funding

37. Macmillan supports the principle of fairer funding in social care, however we are strongly opposed to the unfair proposal to use current benefits funding streams to help pay for the new National Care Service (see answer to question 3).

Making the vision a reality

Question 2: We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- (a) Do you agree?
- (b) What would this look like in practice?
- (c) What are the barriers to making this happen?

38. Macmillan welcomes the emphasis that the Green Paper puts on joint working between local public services, however we would like to see a stronger Government commitment to enabling and encouraging local services to work together. We believe that a new model for social care will only be effective if joint working between health and social care is encouraged by aligning priorities, targets and performance measures more closely. We are encouraged that the Ministerial Group on Integration of Health and Social Care Services is developing a strategy to support local leaders in making sure that services are joined up, and urge that this includes specific proposals on removing the obstacles to joint working.
39. We believe that joint working not only creates a better experience for individuals, but can potentially also produce cost savings.

Case study – Macmillan Social Care Coordinator, Northampton

In February 2008, Macmillan began funding a Social Care Coordinator based at Northampton General Hospital in the Centre for Oncology. The post aims to enhance and improve the experience of people living with cancer across the health and social care journey by streamlining services, facilitating timely hospital discharge and preventing avoidable admissions to hospital.

The service places the patient at the centre of their care. The social care needs of patients, carers, children and families are assessed, advice and information offered and support services co-ordinated.

During the first year of the post, 226 patients accessed the service. By coordinating services and promoting joined up working between health and social care, in this time the Social Care Coordinator is estimated to have facilitated 113 hospital discharges, influenced 18 avoidable admissions and saved 287 excess bed days. Based on a cost of £321 for an oncology bed day, this equates to an estimated £92,127 saving to the NHS on bed days alone.

40. Joint commissioning and the use of pooled budgets should be used to encourage joint working between health and social care. Currently these practices are not being used as much as they could be: in 2007-08, councils only contributed an average of £12.52m to pooled budgets, yet spend an average of £100m a year on adult social care³⁴.
41. Local Strategic Partnerships (LSPs) have a key role to play in ensuring better joint working in care and support services. We support the Equality and Human Rights Commission's proposal that LSPs and their members assume an explicit role to help shape, manage and sustain local care and support infrastructure, with success measured through Comprehensive Area Assessments³⁵. We believe that LSPs should be required to consider the health and social care needs of people affected by cancer specifically.
42. Current levers for encouraging joint working between local authorities and health services are not sensitive enough to the needs of people living with cancer. Local Area Agreements (LAAs), which set out the priorities for local authorities, very rarely mention the needs of people with cancer. Health priorities, such as the Cancer Reform Strategy, which has a strong emphasis on supporting the social care needs of people living with cancer, cannot be incorporated into LAAs. Our concern is that if LAAs do not include any of the indicators which could improve services for people living with cancer, then their needs will continue to 'fall between the gap' in health and social care provision. Local Area Agreements should be more flexible and responsive to the NHS annual operating framework, so that initiatives like the Cancer Reform Strategy are considered in the commissioning of social care services. Joint Strategic Needs Assessments should also be required to consider the health and social care needs of people affected by cancer explicitly, under the indicator on supporting people with long-term conditions.
43. Health and social care services should work together to commission for whole care pathways, instead of for discrete services, and shared outcome measures should be developed across health and social care, which could be incorporated into Local Area Agreements. The Year of Care pilots for diabetes services showed the benefits of commissioning for whole care pathways. The pilots aimed to strengthen the relationship between healthcare professionals and people with diabetes by working to jointly plan their care and to ensure that the local support services were identified and available. Feedback from the pilots has been extremely positive; one service user commented: *"My doctor wants my input as well, he wants to know how he can help me, so it really is a two-way conversation. I now know how I can help myself and how they can help me. As well as the support of my husband and my family, I feel like the practice is also fully behind me."*
44. The principle of 'joined up working' between local public services should also extend to voluntary sector organisations. As care and support becomes more responsive and personalised to individual needs, the types of services that people access will change. We see the voluntary sector as a key partner in responding to and realising that change, not just as contractor for services commissioned by the statutory sector,

³⁴ York Consulting (2008). *Local Government Association/Association of Adults Social Services Report on Adults Social Services Expenditure on 2007-08*. **and** Leeds: York Consulting 47 Source: Information Centre (2008) *Personal social services expenditure and unit costs. England 2006-07, section 5.*

³⁵ Equality and Human Rights Commission (2009). *From safety net to springboard*.

but by being involved in the commissioning process and helping to shape the provision of statutory services.

45. As well as working together, and with the voluntary sector, health and social care services should work with service users to develop services. User involvement is a key lever for improving the quality of care in health and social care services and delivering person-centred care.
46. More value should be placed on volunteer and peer-to-peer schemes in providing support to people living with cancer and carers with low level social care needs. In addition to increasing funding for social care, another way of increasing resource would be to develop volunteering opportunities for people who are not carers but wish to volunteer in health and social care. We see volunteering as a way of providing simple practical and emotional support, such as befriending and help with DIY. We would caution that volunteer schemes, whilst increasing resource, are not free, or a way of providing social care 'on the cheap', and volunteers should not be seen as a substitute for appropriate professional care. Again, local authorities should be supported, and properly incentivised and rewarded initially to see the benefits of using volunteers for such services. A new performance indicator should be introduced for Local Area Agreements and Comprehensive Area Assessment concerning performance on encouraging volunteering.

Case study – Oxfordshire Befriending Network

Macmillan has funded the Oxfordshire Befriending Network (OBN) for a number of years. The service provides trained volunteers to offer practical and emotional support to anyone with a terminal diagnosis or life-threatening illness, at home, in hospital or in a hospice. Befrienders meet weekly to listen, talk, and just be with their befriending partner. They can accompany their partner on hospital visits or other trips, provide a link with local health and social services, and provide much-needed breaks for carers.

In 2004, the OBN won The GlaxoSmithKline Impact Award. The judges praised the way the service benefits both befriender and partner and helps people deal with the taboo surrounding death.

“I am so grateful for the learning I have had from knowing my befriending partner and her sharing some of her life and experiences with me. I have realised how important this has been to both me and her, to see what a difference we have made for each other.” – Volunteer

Funding options

Question 3: The Government is suggesting three ways in which the National Care Service could be funded in the future.

- (a) Which of these options do you prefer, and why?**
- (b) Should local government say how much money people get depending on the situation in their area, or should national government decide?**

47. Macmillan believes that the Government needs to increase resourcing and ensure that resources are used more effectively in order to realise a new vision for social care. However, without knowledge of the economic modelling behind each of the funding options in the Green Paper, setting out the likely costs to the individual in each scenario, we do not feel in a position to make specific comments on the options.
48. However, we are strongly opposed to the proposal contained in the Care and Support Green paper to merge the Attendance Allowance (AA) funding stream with current social care funding streams to pay for the new National Care Service. As the Disability Minister himself said in a written answer on 23 July 2009, *'Attendance Allowance provides help with the disability-related extra costs of people who experience the onset of disability after age 65'*³⁶; it is not intended to pay for the cost of care.
49. People living with cancer that we spoke to rely on AA to help them meet the extra costs they have because of their cancer; to pay for, for example, the cost of travelling to hospital for treatments, car parking charges, or a special diet or clothes because of their cancer or treatment³⁷. They said they greatly valued the flexibility of AA, to spend the money on things that made a difference to them as individuals. In one example, somebody used their AA to pay for modifications to their car to make it easier for them to drive, and another bought Body Butter, to ease the symptoms of lymphoedema. AA allows those that receive it to maintain a certain standard of living, independence and quality of life whilst living with cancer, as it is intended to do. For many of the people we spoke to, AA was the only benefit they get. Taking it away would mean their standard of living, their independence and their quality of life would be reduced because of their cancer. We believe that is unfair. The removal of AA should not be considered under proposals to make the care and support funding system 'fairer', and we will continue to oppose it vigorously.
50. Further, we are concerned that, while the current economic modelling for the National Care Service assumes only drawing in the Attendance Allowance funding stream from existing benefits funding streams, the Green Paper does not rule out other disability benefits being used to help pay for the new system. We will strongly oppose moves to scrap any of the disability benefits that are so valuable to people living with cancer and their carers.

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³⁶ HC Deb, 23 June 2009, c816W

³⁷ Thirteen in-depth interviews were carried out with people living with cancer and carers during August and September 2009