

Macmillan Cancer Support

Response to the Carers Strategy refresh

September 2010

Introduction

Macmillan works to improve the lives of people affected by cancer, including carers. We provide information and support for family and friends who are caring for someone with cancer. This support is provided through local carers support and benefits advice services, our phone service and website, and resources for carers. We provide carers' support services in partnership with other voluntary organisations, primary care trusts and local authorities. We also run befriending and bereavement services that link carers with volunteers who can give one-to-one 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 welcome the opportunity to contribute to the Government's 'refresh' of the Carers Strategy. Macmillan's response focuses on the following outcomes and makes recommendations for the priority actions to achieve each outcome:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity

Outcome 1: "Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role."

1.1 We believe that to achieve this outcome, the 'refreshed' strategy should prioritise the following:

- **Greater identification of carers by the NHS, and signposting to sources of support, including statutory social care services**
- **Statutory support for carers' training and skills programmes**
- **Greater integration of health and social care services**
- **Increased support for vulnerable and seldom heard from carers.**

We set out our reasons for identifying these priorities, and give examples of how they can be implemented, in the section below.

1.2 Greater identification of carers by the NHS, and signposting to sources of support, including statutory social care services.

1.2.1 People living with cancer usually enter the system through the NHS rather than the social care system. This means that carers of people with cancer frequently miss out on carers' assessments, and the support and services arising from them. A study by Macmillan found that only one in five people with cancer feel that their carers' needs are met by health and social care services¹.

¹ Macmillan Cancer Support 2006. *Worried Sick: The emotional impact of cancer.*

- 1.2.2 Macmillan believes there should be a legal duty on NHS bodies to identify carers and signpost them to sources of support, including local authority carers assessments.
- 1.2.3 We believe that by working with the voluntary sector, local statutory services can support the identification of carers through the NHS and signpost them to further sources of support. Two examples follow in the boxes below.

CASE STUDY: IDENTIFYING CARERS FOR SUPPORT

Crossroads Care West London provides a carers' support service consisting of a full-time Carers' Rights Worker post, and part-time Carers' Advice Worker. These posts are both funded out of the carers grant by the London Borough of Hounslow, at a total cost of approx. £66,000 per annum.

The Carers' Rights Worker works with the NHS to identify and signpost carers, by training and introducing carers' champions in GP surgeries and Health Centres. Their role is to identify carers, and signpost them to carers' assessments, information and advice as appropriate. The service also has strong links with other health settings, including the local cancer information centre and the local hospice.

From April 2007 to August 2010, the service supported 648 carers with 317 reusing the service. Macmillan is currently exploring the option of enhancing the service by providing funding to increase capacity, including the possibility of match funding from the local authority/PCT.

CASE STUDY: IDENTIFYING CARERS FOR SUPPORT

A partnership has been formed between Action for Family Carers, Macmillan Cancer Support and NHS Mid Essex to develop a carers support service. The service comprises a 1.6 WTE Macmillan Carers Manager and Macmillan Carers Worker to establish a support service for carers of people affected by cancer and other long term life limiting conditions within the Mid Essex area. It will enable carers to continue with their caring role, thus enabling the cared for to be looked after in their preferred place of care. The service will target working carers, vulnerable carers and carers who would not traditionally access services.

NHS Mid-Essex have contributed to the funding for this service for years 1 & 2 – the total cost of the service over three years (including evaluation) is £178 839.

The service will actively seek to work with a range of organisations, groups and individuals, including the NHS, to ensure that working carers and seldom heard from carers are identified and made aware of both their rights and the support available. The new initiative will provide health professionals with training, support and advice to enable them to identify carers and refer on to a specific service.

1.3 Statutory support for carers' training and skills programmes

- 1.3.1 Research suggests that carers who are struggling to cope may discontinue caring duties, thereby increasing the burden on local services. One study showed that 20 percent of patient admissions into care services are precipitated by a breakdown in

the ability of carers to continue caring duties². In the majority of these cases, carers were either too ill to continue with caring duties, or were unable to cope as caring demands increased. Another report identified the negative health impact associated with caring for someone with a long-term health condition; two thirds of carers reported that their health had been affected by caring, and 40% of carers surveyed had an illness or disability themselves³. Carers have sometimes been described as “hidden patients”⁴.

- 1.3.2 We believe that carers need to be empowered and supported to lead as normal a life as possible, and provided with high quality information, advice, support and coping skills training. In light of the Government’s decision to terminate the Caring with Confidence programme, on the grounds that it was not delivering value for money, we believe other initiatives must be supported in its place to ensure that carers get the support they need. We would welcome the opportunity to work with the Government to increase the provision of training to carers of people with cancer. We are developing a self-management support intervention for carers of people with cancer, and would welcome the chance to explore its potential with the Government and local level stakeholders. The intervention is described in the box below.

CASE STUDY: SKILLS TRAINING FOR CARERS

Macmillan is working with Coventry University to develop and test the feasibility and effectiveness of a self-management support intervention for carers of people with cancer. The purpose of the intervention is to increase the coping skills of carers, through the provision of lifestyle skills training to support self management in order to improve the quality of life of both the carer and the cared for.

This intervention will be based on one already developed by Coventry University, called Help to Overcome Problems Effectively (HOPE). The HOPE course has previously been delivered to people living with a range of long-term health conditions including cancer, and carers of adults and children/adolescents living with LTHCs such as dementia and ADHD. All HOPE programmes have been evaluated and results are positive showing that after attending the HOPE programme participants are more hopeful and optimistic and less depressed and anxious¹.

1.4 Greater integration of health and social care services

- 1.4.1 We welcome the coalition Government’s recognition of the urgency needed in the reform of the social care system⁵, and we look forward to the publication of their vision for the system later in the year. 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 would like to see a strong Government commitment to enabling and encouraging local services to work together, for example through aligned outcome measures in the NHS and Social Care Outcome Frameworks.

² Castleton, Dunstan, Mattocks, and Rowett, 2003. Whole system approach: from pilot to practice. Quality in primary care, 2, 11, 91 - 95

³ Keeley and Clarke 2003. *Primary Carers – identifying and providing support to carers in primary care*. The Princess Royal Trust for Carers.

⁴ Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality. The Caregiver Health Effects Study. Journal of the American Medical Association, 282, 2215 – 2219.

⁵ HM Government 2010. *The coalition: Our programme for Government*.

1.4.2 Joint working not only creates a better experience for individuals, but can potentially also produce cost savings. Joint commissioning can help agencies to work together to:

- develop more integrated and co-ordinated services
- ensure value for money and efficiency
- tackle the 'grey areas' at health and social care boundaries e.g. support for carers
- share intelligence about needs
- target services to give the greatest impact
- raise the profile of carers with the aim of improving access to services
- avoid duplication of services
- share expertise and best practice

CASE STUDY: AN INTEGRATED MULTI AGENCY SERVICE

In 2004, NHS Argyll and Clyde, West Dunbartonshire Council, Argyll and Bute Council, and Macmillan Cancer Support formed a partnership to develop a practical and emotional support service for people living with cancer and their carers.

The resulting West Dumbarton Macmillan Carers Service is housed within the homecare section of West Dumbarton Local Authority, which is the host organisation. Paid carers provide flexible, tailored support in the home to people living with cancer, which enables informal carers and family members to have a break from caring.

The organisers of the Macmillan service work in partnership with the homecare organisers from West Dumbarton Local Authority. This allows packages of care to be shared, enhancing continuity of care and enabling patients to remain at home for end-of-life care if desired. The primary healthcare teams also work with the Macmillan service by referring families to the service and sharing care. The service is well utilised by the local Clinical Nurse Specialists who provide in-house education for the Macmillan carers. The service also refers clients to the West Dunbartonshire Macmillan Benefits Project, a partnership between the Local Authority and Macmillan Cancer Support.

The West Dunbarton Macmillan Carers Service is well established, respected and integrated within the local health, social care and voluntary sector. On average, the current service receives 16 new referrals per month, supports 60 families and provides 225 care hours per week.

The service is now being developed and enhanced by introducing volunteers to support identified aspects of service delivery. This will enable the current service to respond more effectively to the needs of increasing numbers of people with cancer and their carers, in particular working carers and people living alone. This development is the first pilot of its kind hosted by a Community Health Care Partnership. (CHCPs have been introduced across Scotland to manage a wide range of local health services delivered in health centres, clinics, schools and homes. This involves health and social care working in partnership with the voluntary sector to integrate services at a local level.) The financial plan for the service includes pick up of the funding by West Dunbarton CHCP and Argyll and Bute CHCP.

It is estimated that an additional 249 people per year diagnosed with cancer may benefit from the carers service and over 100 people per year could be supported by volunteers.

1.5 *Increased support for vulnerable and seldom heard from carers*

- 1.5.1 Tackling inequalities in the services provided to carers was a gap in the 2008 strategy. One of Macmillan's priorities is support for vulnerable and seldom heard from carers. These include carers with mental health problems, carers from BME communities and young carers, all of whom may be missing out on the help and support available. Other carers who are prone to social exclusion are those who are caring for someone with complex support needs e.g. a dual diagnosis, such as cancer and learning disabilities, or cancer and mental health problems.
- 1.5.2 We believe the 'refreshed' strategy should clearly set out steps for the provision of support to vulnerable and seldom heard from carers. An example of a service Macmillan provides to support these groups is in the box below.

CASE STUDY: SUPPORTING VULNERABLE AND SELDOM HEARD FROM CARERS

Macmillan has been working with The Carers Centre for Brighton and Hove since 2001 to support carers of people with cancer. The partnership has focussed particularly on supporting hidden carers including male carers, carers from BME communities, young carers and carers with mental health problems. Macmillan funded the delivery of two projects. The first was a Macmillan Volunteer Project Co-ordinator with a team of volunteers to support carers through the bereavement process. The second project is an Outreach and Support Worker for cancer carers providing emotional support, information, advocacy and casework, targeting seldom heard from carers as well as providing outreach and training for community groups and professionals.

Macmillan and The Carers Centre for Brighton and Hove are now building on the success of the Outreach and Support Worker service, to develop a service that focuses on a wider group of carers, i.e. carers of people with a range of life threatening conditions including cancer. Macmillan and Brighton and Hove PCT and Local Authority are funding a full-time Outreach and Support Worker. This post is not additional to the resources currently held in the Carers Centre but will enable a re-focussing of the work. The service will provide emotional support for carers and some time-limited support during the transition period (bereavement, move to care home, return to work) when their caring role changes or ends. Established links will be extended in order to develop relationships with carers and professionals across the whole range of end of life care situations.

The total funding for the service for 17 months comes to £58,000 with the PCT contributing half of salary and management fee from the carers breaks money.

Outcome 2: "Carers will be able to have a life of their own alongside their caring role."

- 2.1 **We believe that to achieve this outcome, the 'refreshed' strategy should prioritise the following:**

- **Improved provision of respite care in the community.**

We set out our reasons for identifying this priority, and give examples of how it can be implemented, in the section below.

2.2 *Improved provision of respite care in the community.*

2.2.1 High quality flexible respite care to support the carers and family of people with cancer can help to prevent carer breakdown. We were hugely supportive of the £150m Government funding that was given to PCTs in the 2008 strategy to provide respite breaks to carers. However, we were disappointed to learn that much of that funding was lost within PCT budgets and not spent on its intended purpose⁶. We continue to support the Standing Commission on Carers' recommendation for evidence to be gathered of how the funding for carers breaks has been spent and on the cost-benefits and improved health outcomes of supporting carers in their caring roles, including the provision of breaks.

2.2.2 We believe a restructured NHS offers an opportunity for the Government to support the provision of breaks to carers within commissioning and monitoring structures. While provision of carers breaks was only Tier 3 within the old NHS Operating Framework (i.e. not mandatory), this Government has an opportunity to ask the new NHS Commissioning Board to ensure that GP commissioning consortia pay due regard to this aspect of care, within its commissioning and payment structure.

Outcome 3: “Carers will be supported so that they are not forced into financial hardship by their caring role.”

3.1 **We believe that to achieve this outcome, the ‘refreshed’ strategy should prioritise the following:**

- **Increased support for working carers, and for carers to return to work, to ensure that carers are not forced into financial hardship.**
- **Increased access to financial advice and support**

We set out our reasons for identifying these priorities, and give examples of how they can be implemented, in the section below.

3.2 *Increased support for working carers, and for carers to return to work, to ensure that carers are not forced into financial hardship.*

3.2.1 Macmillan’s carers’ services have reported a trend towards supporting increasing numbers of working carers. As they are of working age, many of these carers have other responsibilities such as dependent children. In the current economic climate, it is essential that working carers are supported to remain in work to ensure that they and their families do not fall into financial hardship, and to avoid increased demand on the benefits and welfare system.

3.2.2 We believe the Government should do more to raise awareness among employers of the specific needs, and rights, of carers, and share good practice regarding supporting carers to combine work and caring. We are very willing to help support this work, and have developed a number of awareness-raising tools that could be promoted. These are outlined in the box below.

⁶ Princess Royal Trust for Carers and Crossroads Care, 2009. *No breaks for carers: A report on Primary Care Trusts and the Carers Strategy.*

CASE STUDY: RAISING AWARENESS WITHIN THE WORKPLACE

Macmillan has developed a 'Cancer in the workplace' e-learning programme, face-to-face course and training pack with Unionlearn (who work with all TUC members). The aim is for TUC members to train their union reps in the workplace to better support employees who have cancer or who are caring for someone with cancer. The course is also available on Macmillan's training website, *Learn Zone*, as two versions - one for employers and the other for employees. Macmillan is now working with the Unionlearn education leads to roll the resource out regionally.

Macmillan has also developed a number of resources to provide information and support to employers and employees who are either directly or indirectly affected by cancer. These include 'Working while Caring for someone with Cancer' and 'Working through Cancer: A guide for employers'. These resources were piloted with three corporate partners between September 2009, and the pilot ran until July 2010. A recent evaluation showed that the resources provided employers and employees with a detailed understanding of having cancer and how it impacts on everyday and working life.

3.3.1 *Increased access to financial advice and support*

3.3.2 Welfare reform is being covered separately from this refresh, but it is important that carers access the financial support that is available. Research carried out by Macmillan earlier this year showed that in England 39 per cent of people dying from cancer are not claiming Disability Living Allowance or Attendance Allowance⁷. The knock-on effect of underclaiming of DLA and AA is that carers miss out on Carers Allowance, as this benefit can only be claimed if the cared for person is in receipt of disability benefits. Carers need information and advice to access the full range of welfare benefits available to them.

3.3.3 Early provision of financial support and advice services can help prevent major financial issues such as debt, bankruptcy and house repossession⁸. Clients of Citizens Advice Bureaux have described improvements in their health as a consequence of receiving help and advice. They felt better; were less anxious, less stressed and less worried about money⁹.

3.3.4 We believe the Government and local authorities have a role in supporting the provision of welfare rights services to carers. Macmillan has developed a network of financial support and advice services in partnership with the NHS, local authorities and Citizens Advice Bureaux among others. These services provide specially trained benefits advisers who can promote and support people affected by cancer, including carers, to access appropriate financial help.

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http://www.macmillan.org.uk/Aboutus/News/Latest_News/CancerPatientsLoseOutOnMillionsOfUnclaimedBenefits.aspx

⁸ Wilson K, Amir Z, Hennings J, Young A. (2010) *A qualitative exploration of financial concerns, advice, support and coping in people diagnosed with cancer and their carers*. Manchester.

⁹ Citizens Advice Bureau (2005) *Prescribing advice: Improving health through CAB advice services*.

CASE STUDY: WELFARE RIGHTS ADVICE FOR PEOPLE AFFECTED BY CANCER

The Macmillan Welfare Rights Service in County Durham forms part of Durham County Council's Social Inclusion Service. It aims to provide those affected by cancer, including carers, with comprehensive, free, confidential and impartial advice and information on their entitlement to social security and housing benefits, tax credits and grants at appropriate points in the patient pathway. The service provides casework and representation to those affected by cancer; provides social care and health staff and volunteers with training and information; and identifies people from vulnerable groups for service provision and signposting.

During the course of 2009-2010 the service opened 1236 cases, which resulted in 1353 successful claims to benefit. Over £3.5m worth of benefits were generated for clients through casework and representation. The service also provided basic benefits training to 40 Macmillan volunteers throughout County Durham.

Outcome 4: "Carers will be supported to stay mentally and physically well and treated with dignity"

4.1 We believe that to achieve this outcome, the 'refreshed' strategy should set out steps for following priority action:

- Increased provision of emotional support for carers
- Increased signposting to self-help and support groups

We set out our reasons for identifying this priority, and give examples of how they can be implemented in the section below.

4.1.1 Increased provision of emotional support for carers

4.1.2 A 2007 evaluation of 28 Macmillan-funded carers' services found that the demand for emotional support from both carers and patients was as high as the demand for practical support. Macmillan's 2006 report *Worried Sick: The emotional impact of cancer* found that a quarter of carers of people with cancer feel abandoned, and two-thirds experience anxiety.

4.1.3 Carers of people with cancer are likely to become more distressed and develop psychiatric morbidity as illness advances and treatment is palliative¹⁰. Macmillan carers' services have identified a need to provide ongoing emotional support to carers post-bereavement, as carers have reported feeling abandoned once their caring role has come to an end and support services stop.

4.1.4 The 2008 strategy recognised the important role that the third sector plays in providing emotional support to carers. We believe the Government should continue to work in partnership with the third sector to increase provision of emotional support services to carers.

¹⁰ C. Pitceathly, P. Maguire. 2003. *The psychological impact of cancer on patients' partners and other key relatives: a review*. In *European Journal of Cancer* - July 2003 (Vol. 39, Issue 11, Pages 1517-1524, DOI: 10.1016/S0959-8049(03)00309-5)

CASE STUDY: BEREAVEMENT SUPPORT FOR CHILDREN AND CARERS

SeeSaw, an Oxfordshire children's grief support service, provides advice, guidance and support to children and their carers where a parent or sibling has died or is dying. SeeSaw uses volunteer support workers who provide a free service with an estimated value in 2007 of £24,000.

The Macmillan Children and Families Support Worker provides training, support and guidance to professionals working primarily with children where a parent is dying, alongside direct support to families. This involves working with schools staff, nursing and medical staff among others.

The scheme has helped communication within the family and led to reduced bereavement support at a later stage. It has also demonstrated the need for continuity of care from before death to throughout the bereavement process. There is anecdotal evidence that there is now greater awareness of children's needs within end of life care settings. Professionals feel supported and have greater confidence in communicating with patients, children, carers and parents.

SeeSaw's services helps the local PCT to deliver the NICE guidelines on palliative care – professional support for families and carers, accessible from all settings, ideally in partnership with the voluntary sector. Since 2008, Oxfordshire PCT and a local hospice charity have made 3 year grants, in part to cover the cost for the pre-bereavement service.

CASE STUDY: A BEFRIENDING SERVICE FOR CARERS

Macmillan Cancer Support, Hull Churches Home from Hospital and Hull PCT have been working on a joint carers support service. The Carers Support Scheme offers support to those who are caring for someone who has a life limiting illness or who have a long term condition. The scheme, which is staffed by two Macmillan project workers and an administrator, also recruits, trains and mentors volunteers who provide much of the befriending and respite offered by the scheme. The scheme also makes referrals for Welfare Benefits checks and will refer on to other services e.g. Community Care, or signpost the carer to other sources of advice and information.

There were a total of 209 referrals for the period April 09 – March 10. In a survey of carers using the scheme, over half responded that it helped them to maintain their own physical and emotional health. Specific benefits identified by carers include "knowing somebody cared" and "ability to have someone listen."

Due to the success of this service, in 2009 Hull PCT picked up the funding in full.

4.2 *Increased signposting to self-help and support groups*

- 4.2.1 Health and social care professionals should identify and signpost carers to local self help and support groups who can provide vital support which may not be available from larger organisations and services.

- 4.2.2 Macmillan supports over 900 independent self-help and support groups, including groups for carers. The support provided by Macmillan includes start-up and development grants, training and resources.

CASE STUDY: SELF HELP AND SUPPORT GROUPS

Carers in Cancer was formed in 2008 as a self-help and support group specifically for carers looking after someone with cancer. It offers carers emotional support and signposting, via a dedicated website. Its services are delivered by trained volunteers, mainly prior carers who have direct experience of some of the challenges faced by carers of people with cancer.

Since 2009 the service has supported 100 carers, ranging in ages from 18 to 70, via email, telephone or the website. With no offices and membership made up entirely of volunteers, the group runs on voluntary donations or grants for specific projects. The running costs are less than £5000 per year. It is currently developing a buddy and befriending service after completing a pilot study in 2009/10.

Charlotte Argyle
Carers Support Manager
Macmillan Cancer Support
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