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CANCER SUPPORT**

<b>Briefing for:</b>	<b>Health and Social Care Committee.</b>
<b>Purpose:</b>	<b>Macmillan's response to the Consultation on the Social Services and Well-being (Wales) Bill.</b>
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### **Introduction**

Macmillan welcomes and supports the Bill to reform social services and social care in Wales. Cancer is a health and social care issue due to the impact the disease can have on the whole of people's lives and also the needs of carers and the wider family.

There are three phases where people affected by cancer may have social care needs; when undergoing treatment, after active treatment has finished and at the end of life. Some people with cancer may have complex social care needs due to the length of treatment, the impact of treatment on their mobility, which affects their ability to perform daily tasks, as well as having emotional and financial needs.

Macmillan supports the Bill's aim to provide a more citizen-centred, integrated, accountable and consistent service across Wales. It is vital that people's individual needs are assessed, that relevant and accurate information and support is provided for people to understand their rights and options, and that carers are also supported.

For many people, cancer is still a short-term incurable illness, but for thousands of others, their experience of cancer is evolving into a long-term condition. In Wales, nearly 18,000 people are diagnosed with cancer every year and more than 120,000 people are living with or after cancer, around 4% of the population.<sup>i</sup> If current trends continue, by 2030 this will have almost doubled to 220,000, more than 7% of the population.<sup>ii</sup>

The good news is that 49%<sup>iii</sup> of people are now surviving for more than 5 years following diagnosis – many of these will need support to live well and as independently as possible with their cancer or the consequences of the treatment. Sadly, 51% do not survive for more than 5 years and will need support to die in the place of their choice, most often their home. This means more people will need person-centred support to live well and die well in the community.

This briefing highlights the key policy areas within the Social Services and Well-being (Wales) Bill that impact on people affected by cancer, which includes patients, carers and relatives.

Macmillan would be prepared to give oral evidence to the Committee.

## People affected by cancer have social care needs

People affected by cancer fall within the definition of well-being within section 2 of the Social Services and Well-being (Wales) Bill due to the physical, emotional, social and economic impact of a cancer diagnosis.

### Key Statistics

- 45% of people with cancer say the emotional effects of cancer are the most difficult to cope with.<sup>iv</sup>
- 58% people with cancer feel their emotional needs are not looked after as much as physical needs, and only 44% of people received information, advice, support or treatment for this.<sup>v</sup>
- More than 4 in 10 cancer patients say the financial impact of cancer has made them feel more stressed or anxious.<sup>vi</sup>
- 46% of carers of people with cancer say that caring impacts on their emotional wellbeing and mental health, citing stress, anxiety and depression (half a million people in the UK).<sup>vii</sup>
- Carers help to meet the social care needs of cancer patients, including personal care and emotional support, but 49% of these carers don't receive any support to care.<sup>viii</sup>
- 39% who completed treatment in 2009/10 say that no health or social care professional talked them through the needs they might have.<sup>ix</sup>
- 91% of households with people affected by cancer experience loss of income and/or increased costs<sup>x</sup>;
- 94% experience physical health condition problems in their first year after treatment.<sup>xi</sup> and
- 78% of people with cancer have experienced at least one physical health condition in the last 12 months which can occur as a result of cancer or its treatment.<sup>xii</sup>

Whilst improvements in cancer treatment mean that more people are surviving or living longer following their illness, we know that their lives don't return to normal and, for many people, cancer can be a long-term condition that has a significant impact on their wellbeing.

With an ageing population, demand for care is increasing and health and social care services need to evolve to respond to these developments. Many people affected by cancer have both short-term and long-term social care needs that should be considered by local authorities and social care agencies in Wales.

**Emotional and Psychological Impact:** Cancer places many people under extreme emotional and psychological strain.<sup>xiii</sup> At the time of diagnosis, around 50% of people with cancer experience levels of anxiety and depression severe enough to affect their quality of life. In the year after diagnosis, around 1 in 10 people living with or beyond cancer will experience symptoms so severe they need specialist psychological or psychiatric services.<sup>xiv</sup>

**Palliative Care and End of Life:** It is essential that health and social services work together to ensure that people are able to die well and in the place of their choice. It is vital that the

needs of people who require palliative care, and their carers, are considered. We know that 67% of people in Wales would choose to die at home.<sup>xv</sup> But only 26.1% actually do.<sup>xvi</sup> In England and Wales only 1% of people receiving a cancer diagnosis would choose to die in hospital.<sup>xvii</sup> Timely access to social care, as part of a package of end of life care, is often vital to enable cancer patients at the end of life to remain in and die in their own home. Social care could include counselling, advocacy, financial support, home adaptations, psychological and social support and information. When the end-of-life wishes of people with cancer are not met, it can lead to a traumatic experience and a lasting sense of guilt and remorse for friends and family left behind.

**Carers:** In Wales there are 55,000 carers of people living with cancer.<sup>xviii</sup> Caring for someone along the cancer journey can also have an enormous impact on someone's emotional, physical, financial and social wellbeing. Half a million UK cancer carers experience mental health issues such as stress and depression, and 150,000 cancer carers report that their physical health is suffering because of their responsibilities. A study by Macmillan found that only one in five people with cancer feel that their carer's needs are met by health and social care services.<sup>xix</sup> Carers generally are also in less good physical health than the general population and cancer carers report issues such as sleep problems, difficulties with digestion and back pain.

**Survivorship and long-term conditions:** More and more people in the UK are surviving cancer. Today the diagnosis and treatment of the disease is becoming ever more effective as advances in technology and medicines are made. As a result, many more people are living through cancer, with 10 year survival rates doubling over the past 30 years to 46%. For many, cancer is still a short-term incurable illness, but for thousands of others, their experience of cancer is evolving to a long-term condition with many possible outcomes. People can experience chronic illness – such as bowel problems, chronic fatigue, lymphoedema, impotence, infertility and depression – while new cancers or treatment-related conditions can emerge months or even years later which may need social care support. As the nature of cancer changes, so do the needs of people who are affected by it – and the range of health and social care professionals and services required to help meet those needs.

**Financial Impact:** A cancer diagnosis has a significant impact on people's finances and leads to new or increasing debts which affects people's emotional wellbeing.<sup>xx</sup> Over 50% of people with a cancer diagnosis say they are worried about their finances and evidence suggests that financial burdens can increase anxiety and stress, with some people feeling that financial difficulties are 'more of a worry than the cancer'.<sup>xxi</sup> Macmillan's recent report Counting the Cost of Cancer<sup>xxii</sup> highlights the financial impact of a cancer diagnosis across Wales's 22 local authorities. In the last year alone, Macmillan's Welfare Benefit Advisers have helped people affected by cancer claim more than £10 million in benefits.

**Physical Impact:** Cancer can have a significant physical impact on people living with cancer, both during treatment and post treatment. Surgery itself can limit people's physical strength and mobility, either temporarily or permanently, and people with cancer say they can find it difficult to do household chores, experience difficulty in driving or managing alone on public transport and mobility issues.

**Wellbeing: Delivering person – centred care through information, support and self management**

A person-centred approach for health and social care in Wales will mean moving away from focusing on processes, systems and targets to developing services that meet people's needs to ensure their empowered to make decisions and take control.

### Macmillan's definition of person-centred care

Person-centred care means that the needs of the person living with cancer are always at the heart of how services are planned, not the needs of the service providers.

It means treating people with sensitivity and compassion and ensuring that their care is holistic in its planning and delivery.

This care goes beyond the clinical to address wider social, financial, emotional, practical, psychological and spiritual concerns.

Putting people at the centre of care planning means they<sup>xxiii</sup>:

- are given the opportunity to express their views, which are listened to and respected
- receive the care they need, when it is needed, regardless of organisational boundaries – and if a service can't be provided they are told why
- know where and how to access ongoing support and information.

Every person affected by cancer in Wales should be offered an assessment of their needs and the outcome of the discussion recorded within a written care plan and given to them. This assessment should include financial, emotional, psychological and information needs. Tailored and personalised care helps professionals provide support for those most in need, and reduce support to those who are willing and able to largely self-care with support.

Information and support is key to raising awareness and to empower people to make decisions about their future and the services that they need. Macmillan believes that people living with or beyond cancer, and their carers, should have easy access to high quality information and support.

### Key statistics

- Over a third (35%) of people with cancer do not feel confident about how and where to access social care and support;<sup>xxiv</sup>
- Almost four in ten (38%) people with cancer want information, advice and support about the health and social services available, but nearly half of those people (47%) say that they aren't able to get it;<sup>xxv</sup>
- 50% of people living with or beyond cancer say no one talked through their health or social care needs after their treatment finished;<sup>xxvi</sup>
- 61% say they didn't receive any support from key health and social care professionals after treatment;<sup>xxvii</sup> and
- 49% of cancer carers don't receive any support at all to care.<sup>xxviii</sup>

Most people with cancer say they would like more information to ensure they are empowered to make decisions to enable them to live well and independently. It is important that people living with cancer and their carers can take an active role in decisions about their lives. This will help them to self-manage. We know that giving people personalised information and support, and helping them to self-manage, can lead to better outcomes.

When people are well informed they know what symptoms to look out for and what to do to manage their signs and symptoms. If they know what to expect, they worry less, are less likely to seek advice from emergency services and can resolve problems without professional intervention. This philosophy fits in with the Bill's objective to ensure preventative measures and early intervention services are accessibly within the community by putting a duty on local authorities, and Local Health Boards, to provide or arrange for provision which will prevent or delay the development of people's needs for care and support.

**Wales needs a coordinated approach to information for people with cancer and their families, which cuts across both health and social care, to ensure that people can access information at the right time in a place and format that meets their individual needs.**

Macmillan is aware of the Citizen Information Portal project, which is being led by Social Services Improvement Agency. Macmillan welcomes the ambition of this project, but to ensure the success of the portal it is vital that it links effectively with the NHS and third sector organisations.

### **Macmillan Information and Support in Wales**

Macmillan is supporting the development of information and support for people living with and after cancer in Wales in several ways. The information that Macmillan can provide people living with cancer in Wales includes:

#### **1. Through local cancer information and support services**

In 2008, we began a programme of investment to improve access to cancer information and support. We are working with Welsh local authorities to pilot cancer information and support in local libraries. Our coordinators work alongside volunteers to deliver a comprehensive service for local people. We have worked in partnership with the NHS and other voluntary sector organisations to open Macmillan cancer information and support centres in Ysbyty Gwynedd, Glan Clwyd, University Hospital of Wales and Wrexham Maelor Hospital and have set up

Our range of services have been evaluated and we are able to provide clear evidence of the impact that our information services provide people affected by cancer and we would be happy to discuss this further with you.

#### **2. Through Macmillan health and social care professionals**

Macmillan supports a range of health and social care posts, many of which provide information directly or signpost people affected by cancer to other appropriate sources. Macmillan offers an e-learning programme to support health and social care professionals and volunteers to enhance the range of skills needed to provide high quality information and support.

#### **3. Through online, phone line and mobile information services**

Macmillan provides information and support directly over the phone and online to anyone in the UK on 0808 808 0000 between 9am – 8pm Monday – Friday, or via [www.macmillan.org.uk](http://www.macmillan.org.uk). These services give people affected by cancer the opportunity to access information and support 24 hours a day, anonymously and in confidence. Macmillan also runs several Mobile Information Centres.

#### **4. Welfare Rights Advice**

Macmillan funds welfare benefits advisers in many parts of Wales, who can advise people which benefits they are entitled to and to help them fill out lengthy and complex forms. Macmillan's 12 welfare benefits advisers in Wales helped over 2,000 people affected by cancer to access more than £10m in benefits and provided a range of advice on debt, housing, employment and energy efficiency in 2012.

Our welfare benefits advisers can also advise patients on Macmillan grants – one-off payments to help with specific costs. In 2012, 1,917 people in Wales were given Macmillan grants totalling £545,000, to deal with additional costs associated with a cancer diagnosis such as clothes, special equipment, fuel bills, rent and mortgage bills, clothing and household appliances.

#### **5. Macmillan Cancer Information Strategy Lead (Wales)**

Macmillan Wales has invested in a cancer information strategy post, which is hosted by Public Health Wales. The project is to develop a vision for cancer information in Wales. The project will consider information giving in both clinical and community setting to ensure people affected by cancer's needs are met throughout their cancer journey. It will also assess whether the cancer information model can be transferred to other chronic conditions. This post has been involved in discussions with regards to the Citizen Information Portal highlighting the information and support needs of people with cancer in communities across Wales.

### **Key Points**

1. Our vision is for person-centred services for all people affected by cancer in Wales.
2. Every person affected by cancer in Wales should be offered an assessment of their needs, and the outcome from the discussion is recorded in a written care plan and shared with them. This assessment must include reference to financial, emotional, psychological and information needs.
3. People affected by cancer must be at the heart of decisions about their care, and services should fit their needs as a result, and not the other way around. To realise this vision, the provision of high quality information and support is essential to ensure people are able to make informed decisions about their own care if they wish.
4. Timely access to social care services, as part of a package of end of life care, is often vital to enable cancer patients at the end of life to die well and in the place of their choice, most often than not, in their own home.
5. There needs to be increased awareness within local authorities and social care of the significant impact that a cancer diagnosis has on a person's wellbeing and that this can result in them having social care needs. This can also apply to friends and family, especially those who take on the caring role. Local authorities and social care services must recognise that for many people cancer is becoming a long term condition and, therefore, more people affected by cancer will need support to live well in the community.

### **Appendix**

#### **About Macmillan Cancer Support in Wales**

Macmillan Cancer Support (Macmillan) improves the lives of people affected by cancer, which includes carers, relatives, people living with and beyond cancer, as well as those dying of the disease. We provide practical, medical, emotional and financial help to people affected by cancer and push for better cancer care across Wales.



In Wales, Macmillan provides significant support and advice to thousands of people affected by cancer. In 2012 this included;

- More than 250 Macmillan professionals who help people affected by cancer in Wales. We fund a variety of health and social care posts including: Welfare Benefits Advisers; Clinical Nurse Specialists; End of Life Coordinators; Specialist Social Workers Dieticians; Occupational Therapists; GPs; Specialist Physiotherapists; User Involvement Facilitators
- Across the UK Macmillan supports a total of 1616 professionals working in palliative and end of life care, which is 32% of our total Macmillan workforce and 28% of our charitable spend. In Wales Macmillan has more than 50 professionals working in palliative and end of life care, however many of our other professionals, such as Information and Support Coordinators, provide support to people at all stages of the cancer journey including end of life.
- In both 2011 and 2012, Macmillan spent almost £3.1m each year on new services for people affected by cancer in Wales;
- Providing financial advice and support to people affected by cancer through our Welfare Benefits Advisers. Our Welfare Benefit Advisers helped people affected by cancer access £10.1million in benefits last year;
- In 2012 Macmillan provided approximately £545,000 in grants to 1,917 people affected by cancer in Wales;
- We provide face to face support to 527,068 people across the UK through our healthcare professionals;
- We help 132,000 people across the UK through our free phone Macmillan Support Line;
- Macmillan reached over three in four people living with cancer across the UK through our services in 2011.

Macmillan is also a force for change; listening to people affected by cancer and working together to improve cancer care. People who live with cancer are experts by experience. They are a powerful resource; telling us what is needed and what must change. Together we can use this knowledge to make a positive difference to the lives of people affected by cancer. We believe that the voice of people living with cancer needs to be heard at all stages of health and social care services; from the design, implementation to the evaluation of cancer services.

In 2011, we developed an ambitious new strategy. Together with people affected by cancer, we created nine statements that we want everyone living with cancer to be able to say in 2030. We called them Macmillan's 9 Outcomes.



<sup>i</sup> Crude estimates made for the end of 2010 and 2030. Estimates assume any increase is consistent across each nation and remains unchanged over the 20 years, as such they are indicative only, are not statistically reliable and could change as more information becomes available. Internal analysis by Intelligence & Research, Macmillan Cancer Support. Analysis based on data from Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547

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<sup>iii</sup> Together For Health - Cancer Delivery Plan Technical Supplementary Report 2012

<sup>iv</sup> Cardy P, et al. Worried Sick: The Emotional Impact of Cancer. *Research for Macmillan Cancer Support conducted by Opinion Leader Research*. 2006. Macmillan Cancer Support, London.

<sup>v</sup> Macmillan Cancer Support 'Worried Sick: The Emotional impact of cancer' 2006 p12

<sup>vi</sup> Macmillan Cancer Support/ YouGov online (August 2011) survey of 1697 people living with cancer in the UK. 197 respondents from Wales.

<sup>vii</sup> ipsos mori for macmillan cancer support, 2011

<sup>viii</sup> 2011 Ipsos MORI and Macmillan Cancer Support 'More than a million'

<sup>ix</sup> Macmillan Cancer Support/YouGov online survey of 1,495 UK adults living with cancer. Fieldwork conducted 1-16 Aug 2011. Survey results are unweighted.

<sup>x</sup> Macmillan Cancer Support, *The Hidden Price Of Treatment*, 2006

<sup>xi</sup> Elliot J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer*. 2011. 105:511-520.

<sup>xii</sup> Elliot J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer*. 2011. 105:511-520.

<sup>xiii</sup> Carlson L et al. (2004) High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer*

<sup>xiv</sup> National Institute of clinical excellence. (2004) Supportive and Palliative care: The manual. NICE

<sup>xv</sup> Views about dying at home, survey commissioned by Marie Curie Cancer Care, carried out by YouGov, 2008

<sup>xvi</sup> 2007 ONS mortality figures

<sup>xvii</sup> Macmillan Cancer Support. Feb 2010 online survey of 1,019 people living with cancer

<sup>xviii</sup> ipsos mori for Macmillan Cancer Support 2011

<sup>xix</sup> Macmillan Cancer Support 2006. *Worried Sick: The emotional impact of cancer*.

<sup>xx</sup> Pleasance P, Buck A, Balmer NJ, WilliamsK (2006) *A Helping Hand – the Impact of Debt Advice on People's Lives*, London, Legal Services Research Centre

<sup>xxi</sup> 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

<sup>xxii</sup> Macmillan Cymru 'Counting the cost of cancer' 2012

<sup>xxiii</sup> National Service Framework for Older People in Wales,

<sup>xxiv</sup> Macmillan Cancer Support 'Worried Sick: The Emotional impact of cancer' 2006 p7



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<sup>xxv</sup> Macmillan Cancer Support 'Worried Sick: The Emotional impact of cancer' 2006 p7

<sup>xxvi</sup> YouGov online survey of 1,912 UK adults living with cancer. 173 adults in Wales were interviewed. Fieldwork took place between 26 July-9 August 2010. Survey results are unweighted

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<sup>xxviii</sup> 2011 Ipsos MORI and Macmillan Cancer Support 'More than a million'