

 	
Briefing for:	National Assembly for Wales' Health and Social Care Committee
Purpose:	Response to the inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.
Contact:	Helen Powell, Macmillan Welfare Rights Service Redesign Project Lead.
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Introduction

1. I welcome this inquiry into the progress made to date on the implementation of the Welsh Government's (WGs) Cancer Delivery Plan (CDP) by the National Assembly for Wales' Health and Social Care Committee.
2. I have not provided answers to all the questions posed by the inquiry but am looking specifically at the financial needs of cancer patients and the 'Meeting People's Needs' section within the CDP. I will evidence the extent to which the key commitment within the CDP for people affected by cancer to be "***routinely offered the opportunity to access financial advice and support as part of the care assessment and planning process***" has been implemented in Wales. My response to the inquiry is based on the analysis of the Local Health Board's (LHBs) 2012 Local Delivery Plans, LHBs 2012 and 2013 Annual Reports, Progress and Interim Report, the recently published All Wales Cancer Patient Experience Survey (CPES), feedback received from the 13 Macmillan Welfare Benefits Advisers in Wales and from my own experience.
3. Having been involved in benefit advice for 28 years, a Macmillan professional working within Neath Port Talbot for 4 years and the Macmillan Welfare Benefits Service Redesign Project Lead, I am fully aware of the significant impact that a cancer diagnosis can have on people's finances and on their wellbeing.

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Evidence from Macmillan Welfare Benefits Service Redesign Project Wales – CDP 10

4. In 2013 Macmillan Welfare Benefit Advisers supported people affected by cancer gain nearly £13.4 million in benefit income, supporting nearly 3000 people. The Macmillan WBA service clearly highlights the importance of people affected by cancer being provided with benefit advice services.

[Summary of key points](#)

5. Macmillan's vision is that everyone diagnosed with cancer in Wales has the opportunity to access benefits advice and support at the point of diagnosis, and at key stages of their cancer journey. Access to timely and appropriate benefits advice and support can significantly reduce financial hardship, alleviate anxiety and stress, improve quality of life and help people make informed choices throughout their cancer journey.
6. Macmillan warmly welcomed the commitment within the CDP regarding people diagnosed with cancer having access to benefits advice and support because cancer has a devastating impact on people's finances that cannot be underestimated. On average people diagnosed with cancer are **£640 a month worse off** due to loss of income as a result of taking time off work and additional costs associated with cancer, including travelling costs and increased heating bills.
7. Whilst the CDP recognised the importance of people receiving benefits advice and support, there is clear evidence from the first All Wales Cancer Patient Experience (CPES) that this commitment is not routinely being implemented across Wales. The CPES, published in January 2014, highlights only **44% of patients said they had been given enough information about how to get financial help or benefits by hospital staff.**ⁱⁱ Furthermore, none of the LHBs Delivery Plans and Interim Reports make reference to how they will address the requirement in the CDP that cancer patients will be routinely offered the opportunity to access benefits advice and support. This is a particular concern for us.
8. **Macmillan Wales is now calling on the WG to work with LHBs, Local Government and third sector partners, like Macmillan Wales, to ensure people affected by cancer are routinely offered the support they need.**
9. **I endorse Macmillan Wales call for the WG to provide clear strategic direction and leadership, supported by an overarching national all Wales structure for planning, accountability and performance. It should set priorities on an all Wales basis for a three year period until the end of 2016; set up robust monitoring systems to scrutinise and report openly on progress, and use data to direct improvements in order to drive up standards and ensure a consistent approach to improving cancer care in Wales, including patients being offered the opportunity to access benefit advice and support as part of the care assessment and planning process.**

[Why do people affected by cancer need benefits advice and support?](#)

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10. The vast majority of cancer patients experience a loss of income and/or increased costs as a direct result of cancerⁱⁱⁱ and this can lead to new or increasing debts.^{iv} Over 50% of people with a cancer diagnosis say they are worried about their finances,^v with 91% of people affected by cancer experiencing loss of income and/or increased costs.^{vi} These pressures can impact on an individual emotional and mental health, with 41% of patients feeling more stressed as a result, and some people feeling that financial difficulties are '**more of a worry than the cancer**'.^{vii}

Loss of income

11. There are 40,000 people of working age living with cancer in Wales.^{viii} People with cancer find it hard or impossible to work during their treatment and sometimes also beyond treatment because the cancer or treatment can mean they feel tired, weak, in pain, and ill for months, even years, after initial treatment. Of those employed at the time of diagnosis, around 15% will have to stop work altogether while 3 out of 10 will have to change their working status in some way.^{ix} Loss of income is one of the greatest financial implications for people diagnosed with cancer. 43% of those in employment at the time of diagnosis experience loss of income.^x As Macmillan's **Counting the Cost of Cancer** report^{xi} highlights, loss of income is greatest in the first year after diagnosis, when the **average person loses an estimated 20% - £5,500 in Wales – of their employment earnings**. Over five years, the average **loss of income is an estimated £16,500**.

12. In addition, the **Welfare Reform Act 2012** could mean that up to 7,000 cancer patients across the UK will lose up to **£94 a week**.^{xii} As a result of the Welfare Reform it is likely that many cancer patients will have their Employment and Support Allowance (ESA) removed after one year irrespective of whether they are ready to return to work. This will leave some without crucial financial support at a time when they are simply unable to return to work.

Costs associated with a cancer diagnosis

13. The costs associated with cancer cannot be underestimated and can lead to poverty. As Macmillan's report^{xiii} highlights the increased costs for cancer patients in Wales include;

- Travel costs:** affecting 95% of patients and on average estimated £275 per patient in the first year;
- Clothing costs:** which is faced by 40% of patients and costs, on average, £400 over five years;
- Increased bills:** including fuel bills due to the fact that the patient is home more than usual and more likely to feel the cold as a result of treatments such as chemotherapy. Phone and internet bills can rise as people need increased social interaction to combat isolation;
- Cost associated with appearance and body image:** This includes make up to hide scars, wigs, bandanas, scarves, different hygiene products, hair products and creams;
- Additional costs** such as household modification, childcare costs, and overnight costs; and

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- f. **Carers** of people with cancer also cite travel costs as a major expense – 70% of cancer carers don't live with the person they care for, so have to travel to see them, as well as travel costs for hospital visits and taking people to appointments.

“The change in what I can eat was costly as I had a tumour at the base of my tongue and radiotherapy has damaged my saliva glands. It was trial and error to start with and a lot of food was wasted.

“I also felt the cold a lot more when I came home from hospital. We had the heating on most of the time, which doubled our gas bill and we had to dip into our savings.”

Derek, Caerphilly

What is benefits advice and support?

14. The numbers of people affected by cancer will continue to rise in the future. The challenge for the future is to ensure that people receive advice routinely as part of the care and assessment planning thereby meeting their needs at key points on the cancer pathway when research has shown there is likely to be a change in their financial circumstances.

15. This table shows the cancer incidence, prevalence in 2011 and in 2030 across Wales.

Local Board	Health	Betsi Cadwaladr	Hywel Dda	ABM	Cardiff and the Vale	Cwm Taf	Aneurin Bevan	Powys	Wales Total
Total cancer incidence per year (2011)		4,507	2,428	2,988	2,418	1,651	3,454	857	18,303
Total prevalence (2010)		27,100	15,660	18,890	14,520	10,320	20,720	5860	113,070
Total prevalence (2030)		48,830	29,230	33,610	27,090	17,540	36,120	11,570	203,990

16. Benefits advice and support is about income maximisation and managing money effectively. When someone is provided with benefits advice and support it can include a wide range of issues including benefits, employment rights, debt, saving and borrowing, pension rights, fuel poverty and insurance.

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17. Welfare benefits advice services often proactively navigate the benefits system for an individual when their ability to do so is impaired by a medical condition, or offer the appropriate level of support and information to aid an individual's own investigation of their entitlements.
18. For people with cancer, income maximisation and managing money effectively are especially important. Benefits advice and support services can help people to meet the extra costs associated with a cancer diagnosis. Macmillan recently launched a UK wide report called '**Cancer's Hidden Price Tag**'^{xiv} which highlighted that in Wales, **four in five people (86%)** are hit by extra costs as a result of a cancer diagnosis, and, on average, are **£640 a month worse off** (£310 loss of income and £330 additional costs).^{xv}
19. It is also important for people diagnosed with cancer to be able to access specialist benefits advice and support in a timely manner. People affected by cancer often struggle to access generic benefits support and advice provision^{xvi} because of the impact that cancer treatment has, including on mobility, making people fatigue and have a weakened immune system. Although nurses and doctors sometimes offer valuable guidance, benefits advice is a specialist area and people affected by cancer do not always receive it at the most effective time. People affected by cancer often find it difficult to access advice via conventional channels, and when they do, they often find that advisers lack an understanding of cancer, its treatments^{xvii} and the likely impact on their benefits entitlement.

Welsh Government policy on benefits advice and support is not being implemented

20. Whilst the CDP included a commitment that people diagnosed with cancer should be '**routinely offered the opportunity to access benefits advice and support as part of the care assessment and planning process**', which Macmillan Wales campaigned for, there is clear evidence that this commitment is not routinely being implemented across Wales, which is having a devastating impact on cancer patients.
21. At the moment, we know that cancer patients and their families in Wales are not routinely offered access to benefits advice and support when they are diagnosed, or at other strategic points on the cancer pathway, which can cause them anxiety, stress and financial hardship.
22. The recent CPES found that only 44% of patients needing financial or benefits support had been given enough information about how to get financial help or benefits by hospital staff,^{xviii} 7% of patients were given financial information but would have liked more and **49% said they did not get any information** but would have liked some.
23. As the following table shows, the CPES also evidenced that there is variation across Health Boards/ Trusts in Wales, ranging from 28% as the lowest score in Abertawe Bro

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Morgannwg University Health Board to 53% as the highest Health Board/ Trust score at Velindre, as highlighted below.

Question	ABM UHB	ABU HB	BCU HB	CVU HB	CTU HB	HDU HB	Velindre	Wales
Q33 The % of patients given information about how to get financial help or any benefits that they might be entitled to from hospital staff	28%	31%	52%	43%	42%	34%	53%	44%

24. As well as CPES evidence, Macmillan Wales' analysis of 2012 – 2013 LHB Delivery Plans and Interim Reports highlights that none of the plans refer to how their Health Board will address the requirement in the CDP that cancer patients and their families will be routinely offered the opportunity to access benefits advice and support.

25. There is a clear need for people diagnosed with cancer to be referred to benefits advice support as evidenced by Macmillan Wales Welfare Benefit Advice Service. In 2013 Macmillan Welfare Benefit Advisers supported people affected by cancer gain £13.4 million in benefit income, supporting nearly 3000 people. The Macmillan WBA service clearly highlights the importance of people affected by cancer being provided with benefit advice services.

Macmillan's vision for Benefits Advice and Support in Wales

26. We want everyone diagnosed with cancer in Wales has the opportunity to access benefits advice and support at the point of diagnosis, and at key stages of their cancer journey.

27. This vision could be realised through a number of initiatives;
- Embedding benefits advice and support into the cancer pathway through the introduction of ***routine holistic assessment and care planning***;
 - Promoting the uptake of benefits through ***key workers and clinical nurse specialists (CNS) who should raise benefits concerns as a matter of course*** and refer if advice is required;
 - Enabling people affected by cancer right across Wales to have access to ***high quality specialist welfare benefit advice*** from professionals who have the experience and support to deal with a client experiencing the impact of a cancer diagnosis.
 - Ensuring people affected by cancer have ***access to welfare benefit advice in a timely manner***, and often needing to be seen as an emergency appointment, as a cancer diagnosis can lead to dramatic overnight changes in financial circumstances.

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28. Macmillan Wales believes that routine holistic assessment and care planning could play a key role in providing cancer patients and their families and carers with this information and help to access benefit advice and support throughout their cancer journey.
29. Without a detailed discussion on finances many people will mistakenly assume that they are not eligible for benefits when they are. As it stands fewer than half of people with a cancer diagnosis in Wales say they receive benefit advice or support from any source.^{xix} It is therefore important that health professionals (including key workers/ CNS) routinely conduct holistic assessment and care planning to enable people to discuss any financial concerns that they may have as a result of their cancer diagnosis and that the CNS can signpost to suitable high quality advice services, such as Macmillan.

Conclusion

30. As highlighted above, it is vital for people affected by cancer to be offered the opportunity to access benefit advice and support to reduce financial hardship, alleviate anxiety and stress, and improve quality of life. Whilst the CDP commitment around benefits advice and support is supported and commended, it is clear that the WG needs to provide clear strategic direction and leadership, supported by an overarching national all Wales structure for planning, accountability and performance, to ensure commitments are delivered consistently across Wales in relation to benefits advice and support being offered to everybody diagnosed with cancer in Wales.

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ⁱ Macmillan Cancer Support 'Cancer's Hidden Price Tag'.

ⁱⁱ All Wales Cancer Patient Experience Survey page 54 - 55

ⁱⁱⁱ Macmillan Cancer Support (2006) Cancer Costs – the hidden price of getting treatment.

^{iv} 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

^v Monitor internal analysis, based on Macmillan Cancer Support/YouGov (Feb 2010) online survey of 1,912 people living with cancer in the UK. 173 respondents from Wales. Survey results are not weighted.

^{vi} Macmillan Cancer Support, The Hidden Price Of Treatment, 2006

^{vii} 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

^{viii} Macmillan 'The rich picture on people of working age with cancer' 2012

^{ix} Macmillan Cancer Support/YouGov (Feb 2010) online survey of 1,912 people living with cancer in the UK. 173 respondents from Wales. Survey results are not weighted.

^x Monitor internal analysis, based on Macmillan Cancer Support/YouGov (Feb 2010) online survey of 1,912 people living with cancer in the UK. 173 respondents from Wales. Survey results are not weighted.

^{xi} Macmillan Cancer Support, 'Counting the cost of cancer', 2012

^{xii} Macmillan estimates that 7,000 cancer patients could lose up to £94 a week. This figure is based on estimates of the number of cancer patients on contributory benefits who are in the Work-Related Activity Group of ESA or currently claiming Incapacity Benefit but will be placed in the Work-Related Activity Group following the reassessment of all Incapacity Benefit claimants. For more info please see: http://www.macmillan.org.uk/Aboutus/News/Latest_News/Cancerpatientstoloseupto94aweek.aspx

^{xiii} Macmillan Cancer Support, 'Counting the cost of cancer', 2012

^{xiv} Macmillan Cancer Support (2013) Cancer's Hidden Price Tag

^{xv} Macmillan Cancer Support (2013) Cancer's Hidden Price Tag

^{xvi} North Wales Cancer Network, in partnership with the Patient and Carer Liaison Group and Cancer Professionals in North West Wales (February 2010): Are cancer patients getting the information and support that they need? A survey of cancer patients living in Anglesey and Gwynedd

^{xvii} Macmillan Cancer Relief and Social Security Agency (2003). Benefits Access for People Affected by Cancer in Northern Ireland. Macmillan Cancer Relief and Social Security Agency: Northern Ireland.

^{xviii} All Wales Cancer Patient Experience Survey page 54 - 55

^{xix} All Wales Cancer Patient Experience Survey 2013