Macmillan response to DWP consulation - *Accounting for the effects of cancer treatments*

Purpose: **To outline Macmillan's views on DWP's consultation on changes to WCA cancer descriptors**

Contact: **Tom Cottam, Policy Analyst, tcottam@macmillan.org.uk,**

020 7091 2050

Date: **09 March 2012**

Summary

- **Macmillan believes that cancer patients awaiting, receiving or recovering from the most debilitating treatments should be able to receive ESA without a stressful face-to-face assessment**

- **We had some concerns regarding the proposals for changing the ESA cancer descriptors set out in the consultation document. In particular, the use of decision-maker discretion and the requirement of medical evidence**

- **We were pleased with commitments made during the course of the Welfare Reform Bill and are now more optimistic that Ministers have listened to these concerns and are willing to amend their proposals accordingly**

- **We anticipate that any new process will be 'light-touch' and include a 'presumption' that cancer patients awaiting, receiving or recovering from treatment should be in the Support Group. This 'presumption' will be confirmed by evidence provided by a healthcare professional. The role of the decision-maker will be limited to assessing whether the correct evidence has been provided**

- **We welcome commitments made by Ministers that the DWP will work closely with Macmillan to design a new process for cancer patients and write guidance**

- **Alongside changes to the benefits system the Government should focus on ensuring cancer patients have access to tailored vocational rehabilitation services and are routinely offered advice about work from healthcare professionals**

Introduction

1.1 Macmillan Cancer Support improves the lives of people affected by cancer, providing practical, medical, emotional and financial support. We work to raise awareness of cancer issues and have been campaigning for cancer patients to be treated fairly by the benefits system and given the support that they need.

1.2 We also operate a benefits advice service for people affected by cancer. Specialist Macmillan benefits advisers can provide assistance face-to-face or over the phone and help people affected by cancer work out what financial help they could be entitled to receive. We currently have 24 advisers operating a welfare rights helpline and 281 advisers working within partner agencies. In 2011, our grants and financial services identified or gave out a total of £210.6m in grants and benefits for nearly 150,000 people affected by cancer.

1.3 Macmillan welcomes the opportunity to respond to this consultation and supports changes that improve Employment and Support Allowance (ESA) for cancer patients. ESA is a crucial benefit for thousands of cancer patients, but currently too many who are receiving or recovering from treatment are required to undergo a stressful assessment to get support or are missing out altogether. Although, we were unable to support the initial proposals as set out in the consultation document, following Ministerial commitments we are now more optimistic that the Government has listened to our concerns and will amend the proposals accordingly.

1.4 This response sets out the changes that Macmillan believes are required. It is based on the recommendations we made to Professor Harrington's Independent Review of the Work Capability Assessment (WCA), discussions with our benefit advisers and commitments made by Ministers. We look forward to the opportunity to work with the DWP to ensure changes to ESA for cancer patients are implemented effectively and sensitively.

The Government's proposals and their effects

2.1 Macmillan welcomed the clear acknowledgement in the consultation document that the existing provisions within ESA for cancer patients awaiting, receiving and recovering from treatment are inadequate and needed to be extended. We also welcomed the implicit recognition that currently too many cancer patients who are seriously debilitated as a result of their treatment are not being accurately assessed and placed in the Support Group. Evidence from our network of benefits advisers demonstrates that cancer patients who are clearly not able to work or in many case able to undertake work-related activity are being found fit for work or placed in the WRAG.

2.2 Despite this, we have concerns about the proposals for change as set out in the consultation document:

a) The consultation document proposed to remove the current provision that provides immediate access to the Support Group for cancer patients receiving non-oral chemotherapy. Instead, the consultation document proposes to introduce a "presumption" that would *"add an element of discretion into each decision".* Although, we are aware that there are ongoing efforts to improve the quality and consistency of

decision-maker discretion, we do not believe this approach is appropriate for cancer patients who are in the middle of or recovering from particularly debilitating treatment. Cancer patients should not need to worry about being placed in the Support Group when they are in the middle of treatment for cancer, or trying to recover.

Evidence gathered by Macmillan demonstrates that this approach has failed these groups in the past. This is often because those responsible for making the decision, whether it be decision-makers or Atos assessors, do not have the specialist knowledge to understand the impacts of cancer treatments. This often results in inaccurate assessments and cancer patients being place inappropriately in the WRAG or even being found fit for work.

> "Within a few weeks of applying for and being awarded the benefit I began to be contacted by JobCentre plus requesting that I attend a 'work focussed interviews'. This was while I was still recovering from both surgery and a very serious post-operative infection. Receiving a demand to attend a 'work-focussed interview' just weeks after my surgery, while recovering from a nasty infection and awaiting the start of chemotherapy that I knew would be gruelling was extremely upsetting." **Breast cancer patient**

b) The consultation document was unclear on the evidence that would be required from cancer patients in order to demonstrate eligibility under the 'presumption'. The document states that the information required would be evidence confirming the treatment being provided, such as a letter from a GP or consultant. However, it then goes on to say that in a small number of cases, where the evidence indicated that the debilitating effects might be limited, individuals could be invited to a face to face assessment. This suggests that evidence regarding the impact of treatment would also be required.

2.3 Macmillan believes that the evidence required to confirm any presumption should be as factual as possible to aid clear and transparent decision-making and ensure that the burden on patients and healthcare professionals is as limited as possible. We know from our benefit advisers that gathering medical evidence from healthcare professionals can be extremely time consuming and stressful for patients.

2.4 As part of the ongoing consultation process Macmillan has been working with DWP officials in order to identify a workable way forward. We want to ensure that cancer patients awaiting, receiving or recovering from treatment get the support they need in the most simple and least stressful manner possible.

Cancer patients awaiting/undergoing treatment

2.4 We understand that the Government would agree in principle, and notwithstanding the outcomes of this consultation, to the outlined below:

- There would be a 'presumption' that cancer patients awaiting and undergoing the treatments identified by Macmillan's research would be placed in the Support Group for the duration of their treatment.

- This presumption would be confirmed by the receipt of evidence from a healthcare professional (HCP) i.e. oncologist, GP or CNS. This evidence would include the diagnosis, treatment regime and the HCP's opinion on the likelihood that the treatment would have work-limiting side effects.
- Subject to receipt of such evidence, the individual would be placed in the Support Group immediately without further assessment or the need for decision-maker discretion.
- Where such evidence was not available or did not confirm the likelihood of work-limiting side effects, then it would be for the decision-maker to determine entitlement, requesting a face to face assessment if appropriate. We would want to add here that where the prescribed evidence was not provided by the claimant in the first instance the decision-maker should seek to obtain it from their healthcare professional before considering initiating a review and referring the case ATOS.

2.5 Macmillan believes the approach outlined above will limit the need for unnecessary assessments and the inappropriate use of decision-maker discretion, whilst giving significant weight to medical evidence. **Crucially, where the prescribed evidence is provided cancer patients would be placed immediately into the Support Group.** On this basis we welcome commitments given by Lord Freud during debate on the Welfare Reform Bill:

'The intention of our proposals is to introduce a presumption that most people being treated for cancer should be in the support group unless the evidence indicates that, exceptionally, the debilitating effects of treatment are likely to be more limited. We would expect this to increase the number of individuals going into the support group and to reduce the number of people called to attend a face-to-face assessment.' **Lord Freud, 14 February 2012**[1]

Cancer patients recovering from treatment

2.6 The effects of cancer treatment, such as debilitating fatigue, can last for many months and years after treatment has finished. However, evidence from benefit advisers indicates that despite these ongoing side-effects, cancer patients in the post-treatment phase are less well protected than those going through active treatment. As a result, patients recovering from treatment will often be called for reassessment once treatment has finished and expected to fill-out an ESA50 and attend medical assessments when they are clearly still unable to work.

[1] http://www.publications.parliament.uk/pa/ld201212/ldhansrd/text/120214-0002.htm#12021441000102

A prostate cancer patient with severe mobility problems who had undergone radical radiotherapy five days a week for 8 weeks was told to attend a medical assessment when they claimed ESA following treatment. The Atos assessment found them fit for work. They appealed and the decision was overturned but they were placed in the WRAG. When they questioned this decision and provided more medical evidence from their consultant they were told that as they were not terminally ill or receiving chemotherapy there would be no harm to their health from working. Following another Atos assessment the claimant was finally placed in the Support Group.

2.7 Therefore, we are pleased that Ministers have agreed to reassess the process by which cancer patients in the post treatment phase are assessed. This is particularly important given the Government's decision to press ahead with the time-limiting of contributory ESA for those in the Work Related Activity Group to 12 months. During a debate regarding the Welfare Reform Bill the Minister for Employment stated:

"It is very much our intention—especially for those who have finished their treatment but are not yet prepared to return to work—to have a simple system that enables a medical professional to indicate to us that that person is not yet sufficiently recovered to make a return to work. Our proposals are out to consultation at the moment, but our overall clear goal is that, in the vast majority of cases, someone who is undergoing treatment for cancer or is recovering from the aftermath of that treatment should be in the support group." **Rt Hon Chris Grayling MP, 1 February 2012**[2]

2.8 In line with the commitments made by the Minister for Employment, cancer patients recovering from treatment should be dealt with in a similar fashion to the approach outlined above for those awaiting or receiving treatment. **We believe that there should be a 'presumption' that cancer patients recovering from their treatment should be placed in the Support Group.** This presumption could last for a fixed period following treatment, such as six months. It could then be reviewed after a fixed period depending on the seriousness of the patient's condition e.g. six months, nine months etc. This presumption could be confirmed on receipt of prescribed evidence from a healthcare professional.

Gathering evidence

2.9 Macmillan benefit advisers agreed that any new process for assessing cancer patient's eligibility for ESA should be 'light-touch' and where possible avoid the need for an ESA50. Evidence from cancer patients, especially those in the middle of treatment, indicates that for many the ESA50 can be daunting to complete, exacerbate stress and anxiety, and often act as a barrier to claiming ESA altogether.

2.10 **Benefit advisers suggested that a short tailored form could be produced, as is the case with the DS1500, or better use could be made of existing forms such as the ESA113.** Crucially, any forms need to be very clear and explicit about what evidence the patients/healthcare professionals are required to provide so this can be provided at the

[2] http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120201/debtext/120201-0001.htm#12020160000002

earliest opportunity. We accept that where prescribed evidence could not be provided an ESA50 might be necessary, but we believe this should be avoided where possible.

2.11 **With regards to gathering evidence from healthcare professionals about the likely or actual impact of a treatment on a cancer patient's capability to work Macmillan believe that this should be as simple as possible, for instance, a tick box or yes/no question.** We would be happy to help DWP get the views from healthcare professionals and cancer specialists about how this could be achieved.

Cancer and work

3.1 Over 700,000 people of working age are living with cancer in the UK. Over 100,000 new cases of cancer are diagnosed in people of working age each year. More people diagnosed with cancer are surviving and living longer. This means many working age people with cancer are able to stay in work, or return to work after treatment, if they so wish. We also know that vast majority of cancer patients want to work.[3] For many it represents a return to normality and greater economic security at a time when many are facing hardship as a result of their condition.

Barriers to work

3.2 However, it remains the case for the majority of cancer patients, especially those receiving or recovering from the most debilitating treatments, that working during or shortly after treatment will not be possible. Cancer patients tell us that the principal reasons for not staying in work are the debilitating physical and psychological impacts of their condition and its treatment and the practical difficulties, such as having to attend regular hospital appointments. These are set out in more detail in Macmillan's recommendations to Professor Harrington.[4]

3.3 However, we know there are other barriers that prevent cancer patients who might be able to remain in work, or return to work following treatment, from doing so. For instance, many line managers/employers find it challenging to support employees affected by cancer. Macmillan's piloting of vocational rehabilitation services for people with cancer has found that line managers do not necessarily have the knowledge and skills to manage a patient's return to work effectively.

3.4 Research by Macmillan found that almost one in five people who returned to work after their cancer diagnosis (18%) say they experienced a lack of understanding of their needs from their employer or colleagues. Almost half of people living with cancer who were in work when diagnosed (47%) say their employer did not discuss sick pay entitlement,

[3] Macmillan Cancer Support/MORI 2001 report 'Working with Cancer – A survey of people with Cancer - 70% of respondents felt it was 'very important' to continue to work, with a further 13% thinking it was 'fairly important'.
[4] Macmillan's full submission to the Harrington Review: http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/MacmillanRecommendationstoProfessorHarringtonFINAL.pdf

flexible working arrangements, or workplace adjustments when they informed them of their diagnosis. [5]

3.5 In addition, cancer patients do not routinely have access to vocational rehabilitation services, or where services are available they are not tailored to meet the specific needs of cancer patients. NHS cancer services concentrate on supporting people through treatment but rarely provide support to help people to return to work. Occupational specialists who might have the expertise to advise cancer patients about work often do not have the capacity to support patients beyond discharge from hopital. Also, we know that healthcare professionals are not routinely providing advice to cancer patients about remaining in or returing to work. For example, over half of people with cancer (52%) who were in work at the point of diagnosis were not informed by a health professional about the impact their cancer diagnosis might have on their working lives.[6]

The benefits system and work

3.6 We have carried out much research and work in this area, and have substantial evidence of the barriers that people with cancer can face in regards to work. However, we are not aware of any evidence that suggests that automatic access to the benefits system prevents cancer patients who want to work from doing so or acts to "*close off possible avenues back"* to work. This has not been the experience with the existing ESA exemption for cancer patients receiving non-oral chemotherapy which has been in operation since 2008. This view is shared by employers who responded to a Macmillan survey. In total only **1 in 10** employers agreed that cancer patients would be *less* likely to remain in or return to work if they were automatically entitled to out-of-work benefits.[7] It is important to stress that being placed in the Support Group does not prevent claimants from seeking work, doing a small amount of work or accessing back to work support, it simply ensures that this is done of a voluntary basis.

3.7 We would also question the assumption set out in the Government's response to Professor Harrington's recommendations that providing immediate access to ESA for cancer patients receiving the most debilitating cancer treatments would encourage the *"wrong behaviours from employers".* As noted above many cancer patients are not receiving adequate support from employers but we do not believe this would be exacerbated by providing improved access to out of work benefits for cancer patients. In fact the results of Macmillan's survey of employers show that:

- 88% would not consider eligibility for out of work benefits a key factor when deciding if an employee diagnosed with cancer could continue work

[5] YouGov online survey of 1,740 UK adults living with cancer. Fieldwork took place between 26 July-9 August 2010. Survey results are unweighted. Stats quoted here are based on people who have completed treatment for cancer within the last 5 years.

[6] Ibid

[7] Figures are from an online survey of 386 employers from businesses across the UK, conducted by Macmillan Cancer Support in February 2012. Employers from Macmillan's Corporate Partners and 'Work & Cancer Toolkit' contact databases were invited to participate. Figures have not been weighted.

- Only **2%** would be less inclined to provide support to stay in work if they knew an employee was entitled to automatic benefits, compared with **9%** who would be **more** likely to provide support under the same conditions
- **77%** of employers said automatic entitlement to benefits would make no difference in their decision to support employees to continue work.

Action for Government

3.8 Clearly, some cancer patients are able to work during treatment and may find this beneficial; we believe that the vast majority who can work will do so. But the majority will require some time off work during or following treatment. It is these cancer patients who are most likely to enter the benefits system. **For this group the Government should ensure there is a process that enables quick access to financial and practical support via the benefits system while they are undergoing or recovering from their treatment without a stressful assessment.**

3.9 Alongside this, the Government should focus on improving the information and support available to cancer patients to ensure that those who are able to remain in work or return to work after treatment are supported to do so. In order to achieve this Macmillan is calling for:

1. Information and advice on working through or returning to work after cancer treatment to be routinely provided by public services such as the NHS and Jobcentre plus.
2. Specialist vocational rehabilitation services to be provided to support people with "chronic" conditions such as cancer to stay in work. In particular, any new initiatives such as recommendations that come out of the Sickness Absence Review must work for people with cancer.
3. Support to return to work to take account of the specific needs of people with cancer and offer ongoing support during the first months back in work.

Cancer Treatments

4.1 The treatments identified by Macmillan following a consultation with senior cancer clinicians[8] are those that will **more likely than not** lead to debilitating side-effects and thus most likely to have an impact of a cancer patient's capability to work. The reason for arriving at this list was to establish a robust proxy for those groups who should be exempt from the WCA and placed automatically in the Support Group.

4.2 This does not represent an exhaustive list of all those groups whose treatment will have an impact on their capability to work. For instance, many cancer patients who undergo major surgery or radiotherapies not covered, such as radiotherapy for breast cancer, will experience significant debilitation as a result of their treatment, which will make work almost impossible.

[8] Macmillan's full submission to the Harrington Review: http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/MacmillanRecommendationstoProfessorHarringtonFINAL.pdf

4.3 Likewise, there will be cancer patients who are covered by the categories identified who will be able to continue to work or return to work soon after treatment has finished. As was identified by the clinicians who took part in the consultation, the impact of treatment will vary from patient to patient based of a number of factors including, the dosage and toxicity of the treatment or the age and underlying health condition of the patient. Often the exact impact of the treatment can be difficult to predict.

4.4 However, Macmillan believes that there is merit in giving automatic access to ESA to those cancer patients who, according to experts, will more likely than not experience debilitation as a result of their treatment. This approach of identifying treatment proxies has numerous benefits. Most importantly, it provides certainty to cancer patients at a crucial point in their cancer journey that if they have to leave work during treatment they will be guaranteed support. However, this approach also limits the burden on healthcare professionals and DWP/Atos by reducing the need for unnecessary assessments.

4.5 If, instead of expanding this approach to cover other treatment regimes, the Government is minded to review cancer patients on a case by case basis, **we would suggest that any new process for dealing with cancer patients claiming ESA applies to <u>all</u> cancer patients and not just those previously identified.**

Next steps

5.1 Macmillan welcomes commitments made Ministers during debate on the Welfare Reform Bill to work closely with organisations such as Macmillan in the design of a new process for assessing cancer patient's eligibility for ESA and the drafting of accompanying guidance for decision-makers and healthcare professionals. We believe this collaborative approach will be vital to ensure any changes meet the particular needs of cancer patients.

5.2 In addition, we believe it is vital that DWP engage at the earliest opportunity with healthcare professionals and cancer specialists to get their views on the design of the new process and any new guidance. These discussions should also consider whether professionals will need any additional training or information as a result of these changes. The information needs of patients should also be examined. This ongoing dialogue should also include seeking the views of benefit advisers who understand the WCA and have experience of working with cancer patients. Macmillan would be happy to help the DWP engage with professionals.

5.3 We understand that the implementation of changes to the ESA rules will require changes to secondary legislation. In order to provide clarity for claimants and decision-makers alike and reduce the likelihood of appeals we believe that the wording of regulations should be clear and unambiguous. Therefore, as provision of prescribed and clearly defined evidence will result in immediate access to the Support Group, we do not believe it is necessary or desirable for the regulations to make reference to the Secretary of State's discretion. Where this process has been used for cancer patients recovering from chemotherapy it has led to confusion and inconsistent decision-making.

5.4 It will also be necessary to introduce a system to fully monitor and review the implementation of the new process and ensure that it is having the intended

consequence of placing more cancer patients in the Support Group, with fewer being required to attend face-to-face assessments.

Timescales

6.1 We understand there is a convention for changes to regulations to be introduced in April or October. However, given the pressing nature of these changes and the impact that delays will have on the lives of vulnerable cancer patients - especially in light of the decision to proceed with time-limiting of contributory ESA - we believe that the Government should attempt to make these changes at the earliest opportunity.

Annex A – Background to Macmillan's recommendations

Macmillan's recommendations

As a part of Professor Harrington's second independent review of the WCA, Ministers asked that the review consider "eligibility for the Support Group based on different cancer treatments (especially oral as well as non-oral chemotherapy)". Subsequently, Macmillan was asked by Professor Harrington to provide recommendations for how the existing rules could be improved.

Currently certain groups of people treated as having limited capability for work-related activity and are placed in the Support Group without having to undergo an assessment. This group includes cancer patients receiving non-oral (intravenous, intraperitoneal or inthrathecal) chemotherapy.

However, the current system unfairly distinguishes between cancer patients receiving non-oral chemotherapy and those receiving oral chemotherapy or radiotherapy. While the former group are automatically entitled to ESA and placed in the Support Group, all other cancer patients have to undergo an assessment and have no guarantee that they will receive support despite undergoing treatment that can be equally debilitating.

In order to inform the recommendations to Harrington Review Macmillan undertook a consultation with senior cancer clinicians. As a result of this expert consultation, Macmillan recommended that cancer patients receiving equally debilitating oral chemotherapy and radiotherapy should also be exempt from going through the WCA and placed in the Support Group automatically

The experts consulted agreed that these groups would provide a reasonable proxy for entitlement to the Support Group because the treatment would more likely than not result in debilitating side-effects. In order to qualify for this exemption cancer patients would simply have to provide evidence of treatment regime, as is currently the case for non-oral chemotherapy patients.

Macmillan's full submission to the Harrington Review can be found here: http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/MacmillanRecommendationstoProfessorHarringtonFINAL.pdf

DWP response

In response to Macmillan's recommendations, which were endorsed by Professor Harrington, DWP accepted that the existing rules are unfair and that the groups of cancer patients identified by Macmillan's research should not be treated differently by the benefits system.

However, instead of extending entitlement to Support Group to all cancer patients within these groups, the Government proposed to introduced a 'presumption' that such cancer patients should be placed into the Support Group but only following an assessment and ultimately at the discretion of DWP decision-makers.

The reasons given by DWP for moving away from entitlement based on treatment regime were as follows:

- it fails to recognise the variation in debilitation caused by the various types of treatment identified

- it removes the ability or chance for someone to work during their treatment (with suitable support from an employer) if they felt able to do so
- it encourages the wrong behaviours from employers and stigmatising cancer as something that can automatically lead to unemployment or worklessness, rather than encouraging employers to provide support to help individuals to stay in work where possible

Macmillan did not agree with this analysis and did not believe it was supported by evidence from the existing exemption for non-oral chemotherapy patients. Macmillan believes that those cancer patients who are able to work through their treatment should receive the right support to allow them do so. However, cancer patients who have to leave work and rely on benefits should be able to receive support while they are undergoing particularly debilitating treatment.

We welcomed commitments to expand the eligibility for the Support Group and reduce the number of face to face assessments. However, without stronger commitments within the consultation document to protect cancer patients from stressful assessments (especially for those who are currently exempt) and the inappropriate use of discretion and without greater detail about the evidence that cancer patients would be required to provide to satisfy eligibility for the Support Group, Macmillan was unable to support the proposals as they stood and sought further reassurances.