Improving the Work Capability Assessment for Cancer Patients Awaiting, Receiving or Recovering from Treatment:

Recommendations for the Independent Review of the Work Capability Assessment

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Recommendations

1. As a result of the expert consultation we recommend that a cancer patient should be automatically exempt from going through the WCA and placed in the support group if they are:
    - Awaiting, receiving or recovering from treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy; or
    - Awaiting, receiving or recovering from treatment by way of oral chemotherapy, except when the therapy is continuous for a period of more than six months; or
    - Awaiting, receiving or recovering from combined chemo-irradiation; or
    - Awaiting, receiving or recovering from radiotherapy in the treatment of cancer in one or more of the following sites:
        - Head and neck
        - Brain
        - Lung
        - Gastro-intestinal
        - Pelvic
2. When cancer patients receive an ESA50 form for the first time they should be made aware of the need to provide supporting medical evidence from a relevant healthcare professional
3. Decision-makers should be better equipped and more empowered to use discretion appropriately when reviewing whether a cancer patient should be required to undertake the WCA following treatment
4. When a cancer patient's ESA Support Group status is being reviewed decision-makers should routinely carry out a 'light-touch' assessment seeking information regarding their treatment/post treatment condition before deciding whether or not to send out a further ESA50 form

1. Introduction

1.1 As part of the programme of work for year two of the Independent Review of the Work Capability Assessment, the Government asked Professor Harrington, who is conducting the review, to consider whether the existing descriptors for automatic eligibility for the Support Group element of Employment and Support Allowance (ESA) for cancer patients receiving treatment needs to be changed. In January 2011 Professor Harrington asked Macmillan to provide clinically-based recommendations as to how the descriptors could be improved.

1.2 Currently, only cancer patients receiving non-oral chemotherapy (intravenous, intraperitoneal or intrathecal) are treated as having limiting capability for work-related activity and placed in the Support Group for the duration of their chemotherapy, without having to undergo a Work Capability Assessment (WCA). This is in recognition of the highly debilitating side-effects that cancer patients often experience as a result of such treatment, which mean it is highly likely they would be unable to work whilst they are receiving or recovering from treatment.

1.3 However, since the introduction of ESA in 2008 Macmillan has argued that the distinction between a cancer patient receiving non-oral chemotherapy and those receiving oral chemotherapy and radiotherapy is clinically unjustified. There is considerable evidence that oral chemotherapy and certain courses of radiotherapy are often just as debilitating as non-oral chemotherapy.

1.4 To inform the recommendations to Professor Harrington and ensure they are clinically robust Macmillan carried out a rigorous consultation exercise with senior cancer specialists. This paper outlines the outcomes of the expert consultation and sets-out Macmillan's recommendations for extending the criteria for automatic eligibility for the Support Group for cancer patients awaiting, receiving or recovering from treatment.

1.5 Macmillan has consulted a wide range of national cancer charities on the recommendations set out below.

2. Scope

2.1 The scope of this work was limited to considering how descriptors for automatic eligibility for the Support Group should be improved for people receiving treatment for cancer. We were not asked to look at whether there is justification for automatic eligibility for other conditions.

2.2 Macmillan has wider concerns about how the WCA, and in particular the medical assessment, works in practice for cancer patients. We will continue to raise these concerns with the Government and work with Professor Harrington to improve how the WCA works for cancer patients, but we will not be addressing these concerns as part of this paper.

3. Background

The current situation

3.1 ESA was introduced in October 2008 to replace Income Support and Incapacity Benefit for those people who are not in work due to reasons of disability or sickness. After an initial assessment period of 13 weeks, claimants undergo the work capability assessment (WCA). This consists of a self-assessment questionnaire completed by the claimant, followed by a medical examination with a doctor from the DWP medical service to determine if the person has limited capacity for work and is therefore entitled to ESA.

3.2 The *Employment and Support Allowance Regulations 2008*, set out that certain groups of people automatically qualify for ESA (are deemed to have limited capacity for work) without having to satisfy the work capability assessment. Of most relevance to cancer patients this includes people who are:

- terminally ill (i.e. their death can reasonably be expected within six months);
- receiving non-oral (intravenous, intraperitoneal or inthrathecal) chemotherapy or recovering from that treatment,
- receiving radiotherapy or recovering from that treatment (The claimant must be undergoing at least two days of treatment per week, recovering from that treatment for at least two days of treatment per week or undergoing one day of treatment and one day of recovery per week. The two days need not be consecutive).

3.3 Those who qualify for ESA are then assigned into one of two groups after an assessment of whether they are too ill or severely disabled to be expected to undertake work-related activity (i.e. they have limited capability for work-related activity). The test has a list of 46 descriptors, relating to both physical and mental functions. If at least one of them fits, the person is placed in the support group of claimants. If none of them fits they are placed into the work-related activity group (WRAG), where claimants are required to carry work-related activities and attend work-focused interviews.

3.4 Those claimants who have been found to have limited capability for work-related activity are assigned into the support group. In this group claimants are not required to attend undertake work-related activity or work-focused interviews.

3.5 Certain groups of ESA claimants should automatically be treated as having limiting capability for work-related activity and placed into the Support Group without being required to undergo the WCA. Of most relevance to cancer patients, this category includes people who are:

- terminally ill;
- receiving treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy; or
- recovering from that treatment and the Secretary of State is satisfied that the claimant should be treated as having limited capability for work-related activity.

3.6 Under the *Employment and Support Allowance (Limited Capability for Work and Limited Capability for Work-Related Activity) (Amendment) Regulations 2011,* automatic entitlement to the Support Groups was extended to cancer patients who are likely to receive intravenous, intraperitoneal or intrathecal chemotherapy within 6 months. This aims to cover cancer patients awaiting or in-between courses of treatment and therefore should not be expected to look for work.

Why change is necessary

3.7 Since ESA was introduced Macmillan and other cancer charities have argued that the descriptors for those cancer patients who should be treated as having limited capability for work-related activity are inadequate insofar as they exclude those receiving oral chemotherapy and radiotherapy, which can be just as debilitating as non-oral chemotherapy.

3.8 This distinction between treatments is not clinically justified and often appears profoundly unfair to those cancer patients who are undergoing extremely debilitating treatments, but are still required to attend medical assessments in order to demonstrate eligibility for ESA.

3.9 We know that many cancer patients find the WCA, and in particular the medical assessment extremely stressful,[1] especially when they are receiving or recovering from treatment. This was highlighted in the first report produced by the Independent Review, which found that the WCA was "mechanistic, impersonal and lacks empathy".[2]

3.10 The WCA process is not always clear and it can take many weeks or months before a decision is reached. During this time cancer patients awaiting, receiving or recovering from oral chemotherapy or radiotherapy will not know whether or not they will be placed in the Support Group, the WRAG or found fit work. This can cause considerable stress and financial worry at a time when they should be concentrating on their treatment or recovery.

3.11 In addition to the unnecessary stress experienced by cancer patients who are required to undergo the WCA despite being clearly unable to work due to their treatment, there is also significant cost incurred by the Government as a result of carrying out unnecessary assessments.

A woman from South West England required intensive radiotherapy after surgery for cancer. However at the time of claiming ESA, the hospital had not yet confirmed the dates. The woman was therefore required to attend a work capability assessment but when she got there the assessors were 'horrified' that she had been made to attend.[3]

[1] *Failed By The System,* Macmillan Cancer Support, 2010
[2] *An Independent Review of the Work Capability Assessment,* Professor Malcolm Harrington, November 2010
[3] *Failed By The System,* Macmillan Cancer Support, 2010

4. Expert Consultation

Methodology

4.1 In order to provide the Independent Review with a strong, authoritative, and consensual medical opinion about how the descriptions can be improved, Macmillan carried out an expert consultation with senior cancer clinicians. The consultation was carried out online and in total 14 experts (see annex one) participated from a range of different cancer specialisms, including healthcare representatives from other cancer charities.

4.2 The consultation involved three phases:

1. **Phase 1**:Set questions about different forms of treatment, including chemotherapy, radiotherapy and emerging treatment and their side effects
2. **Phase 2**: An online 'bulletin board' enabling respondents to interact with each other and see the responses posted by everyone to a series of questions. This phase was used to summarise the responses provided in phase 1 and to iteratively work towards exemption wording based on a number of criteria.
3. **Phase 3**: Agreement of the final wording for automatic entitlement based on cancer treatment

Once the wording had been agreed by a majority of the senior clinicians it was tested with a number of experienced Macmillan benefits advisers to ensure it workable 'on the ground'.

Chemotherapy

4.3 Currently, only cancer patients receiving non-oral (intravenous, intraperitoneal or intrathecal) chemotherapy are automatically treated as having limited capability for work-related activity. This is based on a belief that invasive chemotherapy is more debilitating in most circumstances that oral chemotherapy. However, this view is not supported by the existing evidence and was rejected by participants in the expert consultation carried out by Macmillan.

4.4 Outcomes from the expert consultation:

1. All forms of chemotherapy are a reasonable proxy for likely debilitation. Chemotherapy is a systemic treatment that can affect the entire body often resulting is severe side-effects. The exception is where oral chemotherapy is administered as long-term or "maintenance" therapies for longer than six months. For example, chlorambucil for low-grade Non-Hodgkins-Lymphoma or methotrexate, which are usually well tolerated.
2. The route of chemotherapy administration (i.e. oral vs non-oral) is not a good proxy for determining likely debilitation. For example, there are cases where oral chemotherapy drugs are more toxic (and hence typically more debilitating) than their non-oral equivalents (e.g. Busulfan used in preparation for a stem cell transplant) or where the same drug can be administered orally or non-orally with the same impacts (e.g. Fludarabine, which is usually given to treat Chronic Lymphocytic Leukaemia.)

''I see no point…in attempting to discriminate between oral and intravenous chemotherapy"
Alastair Munro, Professor of Radiation Oncology

"I would say that oral and intravenous chemotherapies could certainly be considered to be equally debilitating when used in the treatment of breast cancer. Oral chemotherapies might be seen as more 'convenient', however, these drugs have the same (common) side-effects, only the route of administration is different"
Catherine Priestley, Clinical Nurse Specialist, Breast Cancer Care

3. The impact of chemotherapy from patient to patient is highly variable and would be difficult to predict. However, the severity of debilitation is primarily driven by four main factors:
   - The toxicity of the specific chemotherapy drug;
   - The length of time that the drug is administered for;
   - The dosage;
   - The underlying health status of the individual patient.
4. Similar to non-oral chemotherapy, oral chemotherapy can result in a number of side effects, including, severe fatigue, nausea, neuropathy, diarrhoea, plantar palmar erythema, muscostis and increased risk of infection. Almost all oral chemotherapy patients will experience some side-effects. Many side-effects will cease when treatment finishes, but some, such as fatigue, which is the most frequently reported side-effect, can last many months and even years after treatment has finished.

4.5 The views expressed during the expert consultation are supported by studies that compare the impact of oral chemotherapies as opposed to non-oral equivalents. For instance, a study of 1,608 colon cancer patients who were either given oral or IV chemotherapy treatment found that although oral chemotherapy was more convenient the impact on quality of life was no different to those on intravenous chemotherapy treatment.[4]

4.6 It is also important to point out that, despite challenges concerning adherence and safety, oral chemotherapy offers many advantages, including no need for sometimes painful intravenous access, no need for costly hospital visits, more time at home for patients, and a greater sense of patient autonomy. These benefits and advances in drug development mean that oral chemotherapy is being used increasingly instead of non-oral equivalents. A study from the US highlights that in 2007 10% of cancer chemotherapy was prescribed to patients

[4] http://jco.ascopubs.org/content/25/4/424.abstract?sid=397ed46c-c36a-43cf-961a-82c6e63e2cfb

by means of an oral formulation, but, by 2013, this percentage is predicted to increase to 25%.[5]

Radiotherapy

4.7 Currently, cancer patients receiving radiotherapy will be treated as having limited capability for work only under certain circumstances (see 3.2), which means they are automatically entitled to ESA but not automatically placed in the Support Group. Following the WCA they could be placed in either the Support or the WRAG.

4.8 Radiotherapy, unlike chemotherapy, is a targeted treatment and can be in certain circumstances well tolerated. However, the outcomes of the expert consultation carried out by Macmillan indicate that cancer patients receiving radiotherapy for certain cancers are highly likely to experience significant debilitation as a result of their treatment and should therefore be placed automatically in the Support Group.

4.9 Outcomes from the expert consultation:

1. Not all radiotherapy will likely lead to debilitation. For example, radiotherapy for certain skin cancers can be relatively well tolerated.
2. The extent of debilitation is primarily determined by the site of the tumour being treated.
3. Treatment for certain tumour sites, notably head and neck, lung, gastro-intestinal and pelvic, will likely lead to significant debilitation that will in many circumstances be comparable or worse than that experienced by chemotherapy patients.
4. Side effects from particularly debilitating radiotherapy can be severe and long-lasting. Fatigue is the most common and debilitating side-effect. It can last for months and sometimes years following treatment. Most side-effects relate to the site that is being treated:

> *"Radiotherapy to the head and neck and oesophagus causes mucositis (sore mouth and throat) which is painful and prevents normal eating and drinking. As a consequence of this a majority of these patients require morphine based analgesia during treatment and nearly all will require dietary modification and advice (liquid feeds etc). 25% will need some form of tube feeding … and 10% will be admitted to hospital at some stage during the therapy for support"*
>
> **Richard Simcock, Consultant Clinical Oncologist**

[5] http://www.springerlink.com/content/8uj121031851p157/

> *"Diarrhoea, severity varies for each patient, affects most patients having their pelvis treated"*
>
> **Peggotty Moore, Macmillan Specialist Radiographer**

4.10 Below is a more detailed summary of common side-effects resulting from radiotherapy for particular sites:

Cancer site	Common side effects from site specific radiotherapy
Head & Neck[6]	Severe mouth ulcers, sore mouth, swelling in the throat causing problems eating, talking and swallowing (mucositis)
Brain[7]	Seizures, oedema, nausea, hair loss
Chest (Lung)[8]	Swelling and soreness in the throat, nausea, shortness of breath and longer term breathing problems
Gastrointestinal	Nausea, diarrhoea, bowel incontinence, sexual dysfunction, swelling and soreness in the throat and reduced appetite
Pelvic region[9]	Pelvic fractures, nausea, diarrhoea, sexual dysfunction, cystitis, lower back pain, bowel incontinence

Combined chemo-irradiation therapy

4.11 One of the most severely debilitating treatment regimens is when a patient undergoes radiotherapy in combination with chemotherapy.

5. Changes to the Descriptors

5.1 As a result of the expert consultation we recommend that a cancer patient should be automatically exempt from going through the WCA and placed in the support group if they are:

- Awaiting, receiving or recovering from treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy; or
- Awaiting, receiving or recovering from treatment by way of oral chemotherapy, except when the therapy is continuous for a period of more than six months; or
- Awaiting, receiving or recovering from combined chemo-irradiation; or

[6] http://www.cancerhelp.org.uk/coping-with-cancer/coping-physically/mouth/types-and-causes-of-mouth-problems
[7] http://www.cancerhelp.org.uk/about-cancer/treatment/radiotherapy/side-effects/brain/brain-radiotherapy-and-hair-loss
[8] http://www.cancerhelp.org.uk/about-cancer/treatment/radiotherapy/side-effects/chest/chest-radiotherapy-side-effects-swallowing
[9] Andreyev J (2005) Gastrointestinal complications of pelvic radiotherapy: are they of any importance? BMJ. UK

- Awaiting, receiving or recovering from radiotherapy in the treatment of cancer in one or more of the following sites:
  - Head and neck
  - Brain
  - Lung
  - Gastro-intestinal
  - Pelvic

5.2 **Definition of 'Awaiting':** This should reflect the rule for the existing provisions for non-oral chemotherapy patients i.e. applies to patients who are "*likely to receive such treatment within 6 months*" of the time their application for ESA is made.

5.3 **Definition of 'Receiving':** This should reflect the rules for the existing provisions for non-oral chemotherapy patients i.e. for the duration of a planned course of treatment. With regards to radiotherapy the descriptor should apply for the duration of a planned course of treatment irrespective of when or how frequently within that period treatment has been received.

5.4 **Definition of 'Recovering':** This should reflect the rules for the existing provisions for non-oral chemotherapy patients i.e. decision-makers should use their discretion as to whether following treatment cancer patients should, based an their individual circumstances, continue to be treated as having limited capability for work-related activity. See below (paragraph 6.4 – 6.5) for recommendations for how the process should be improved.

5.7 **Definition of 'Continuous':** This should be taken to mean treatment that is part of a single regimen and should not include consecutive periods of treatment that are part of different regimens.

5.8 Extending the automatic eligibility for the Support Group to the radiotherapy patients receiving the treatments outlined above should not change the rules for other radiotherapy patients who are currently treated as having limited capability for work.

6. Changes to the ESA50

6.1 Both the experts who participated in the consultation and a group of Macmillan benefit advisors who were also consulted were satisfied that the recommended wording set out above would be workable in practice. They thought that the majority of patients would be able to self-identify that they fall into one of the categories and supportive evidence could be provided by healthcare professionals to confirm eligibility.

6.2 However, it was also felt that when the cancer patients received the ESA50 for the first time they should explicitly be made aware of the need to submit medical evidence from a relevant healthcare professional to confirm their treatment status and support their ESA claim. Guidance should be made available for both applicants and healthcare professionals that details the circumstances in which a cancer patient are eligible for automatic entitlement to

the Support Group and what supporting evidence is required to demonstrate eligibility e.g. type and dates of treatment etc. This would ensure that supporting medical evidence is provided at the earliest opportunity and reduce instances of unnecessary requests to attend medical assessments.

6.3 We would also like to see changes to how cancer patients recovering from treatment are dealt with. Currently, the period of time that a cancer patient is 'recovering' following treatment and deemed to have limited capability for work-related activity is at the discretion of the Jobcentre Plus decision-maker. Correctly, this recognises that rate at which cancer patients will recover from their treatment will vary significantly from patient to patient. However, the experience of Macmillan benefit advisors is that decisions to call a cancer patient for an assessment following treatment can be taken arbitrarily and with little consideration of the individual circumstances of the claimant. For instance, in many areas it is routine practice to send a cancer patient an ESA50 form and subsequently call them for an assessment as soon as their treatment has finished without due consideration given to whether or not they are still 'recovering' from their treatment. On occasions cancer patients have been sent an ESA50 form even though they are still receiving treatment simply because their treatment has been extended but decision-makers have not sought information before sending out an ESA50.

6.4 We believe that prior to sending out an ESA50 decision-makers should seek confirmation from the claimant (and where necessary the relevant healthcare professional) regarding their treatment status. This could be a simple form that requests information about whether the claimant is still receiving treatment, whether they are awaiting further treatment, whether they are recovering from treatment and what side effects they are experiencing. Based on this information the decision-maker would be able to make an informed judgement about whether it is appropriate to send an ESA50. This would ensure cancer patients are not asked to complete an ESA50 form unnecessarily, which can cause additional stress, especially if the claimant believes their benefit is under threat.

6.5 Macmillan also believes that decision-makers should be better equipped to understand how side-effects can persist following treatment for cancer and more empowered to use their discretion appropriately. Routinely, cancer patients should not be sent an ESA50 following treatment unless the decision-maker has taken steps to satisfy themselves that they are ready to undergo the WCA. Macmillan would welcome the opportunity to work with the Government to improve the guidance and resources available to decision-makers.

7. Annexes

Annex One - List of participants in expert consultation

- Graham Collins, Consultant Haematologist
- Tim Eisen, Professor of Medical Oncology (Phase 3 only)
- Robert Glynne-Jones, Macmillan Consultant in Gastrointestinal cancer
- Rajnish Gupta, Consultant Medical Oncologist and Professor of Cancer Studies at University of Limerick
- Peggotty Moore, Macmillan Specialist Radiographer
- Alastair Munro, Professor of Radiation Oncology
- Pauline McCulloch, Palliative Care Nurse Specialist
- Catherine Priestley, Clinical Nurse Specialist - Primary Breast Cancer, Breast Cancer Care
- Terry Priestman, Consultant Oncologist
- Clare Shaw, Consultant Dietician within Cancer Centre
- Richard Simcock, Consultant Clinical Oncologist and Lead Clinician for Breast Care
- Bhavin Visvadia, Consultant Maxillofacial Surgeon and Clinical Advisor to the Mouth Cancer Foundation (Phase 1 only)
- Kate Wheeler, CLIC Sargent Young Persons Social Worker
- Lilian Wiles, Head of Patient Services for Beating Bowel Cancer (Phase 1 only)