

# Welfare Reform Bill Second Reading Briefing



Purpose: **To brief Parliamentarians on Macmillan's priorities for the Welfare Reform Bill in advance of the Second Reading Debate**

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## Introduction

This briefing sets out the priority issues for Macmillan Cancer Support in the Welfare Reform Bill. While we welcome some aspects of reform – including measures to simplify the benefits system – some proposals will mean people living with cancer will be left without critical financial support at a time when they need it most. The impact of this will be nothing short of devastating.

## Macmillan's three priorities for the Welfare Reform Bill

1. End the current unjust system where the type of cancer treatment someone receives affects how they are treated in the welfare system.
2. Make sure that people continue to receive critical financial support for as long as their disability or long term condition limits their ability to work.
3. Make sure that people with cancer can apply for financial support to help with the extra costs of being disabled as soon as their support needs arise.

### 1. Cancer patients should be treated fairly when placed in an ESA group

*Macmillan believes that cancer patients awaiting, undergoing or recovering from chemotherapy or radiotherapy should be automatically assigned to the ESA Support Group.*

As part of the Welfare Reform Act 2007, the Government agreed that people with cancer who are receiving *non-oral* chemotherapy (e.g. via an intravenous drip) should not have to undergo a medical assessment in order to receive financial support. Instead they are placed directly in the Employment Support Allowance (ESA) Support Group which means they do not have to do 'work related activities', such as job interview practice, to receive their benefit. This was in recognition of the very debilitating effects of such treatment.

However, people with cancer receiving *oral* chemotherapy or radiotherapy must still undergo a medical assessment to determine if they are eligible for ESA. They can still be placed in the ESA Work-Related Activity Group where they must take part in work related activities in order to receive their benefit.

### Why isn't the current system working?

The current system is failing cancer patients and is creating sharp inequities. Patients with the same cancer are being treated differently in the benefits systems depending on how they prefer their cancer treatment to be administered. The main problems are:

- i. **The physical and psychological side effects can be equally debilitating whether the patient has non-oral or oral chemotherapy or radiotherapy –**

these can include severe fatigue – consistently reported by patients as the most disruptive side effect – reduced immunity, vomiting and diarrhoea. Our *Failed by the system* report in November 2009 showed that assessors conducting the medical assessment were “horrified” that a cancer patient waiting for intensive radiotherapy after surgery was required to attend.

- ii. **Cancer treatment is changing with oral chemotherapies being prescribed more often and for more aggressive cancers** – figures from the USA show that in 2007 10% of cancer chemotherapy was prescribed in oral form but by 2013 this is expected to rise to 25%. In short, the current system is not ‘futureproof’.
- iii. **Cancer patients can now often be given the choice of taking the same chemotherapy drug either orally or non-orally.**

### **Oral chemotherapy – the preferred option for patients and hospitals?**

Bengu has received both non-oral and oral chemotherapies in her treatment for Acute Lymphoblastic Leukaemia. She said: “If given the choice I would always choose to take chemotherapy orally. I’ve had so many injections I wouldn’t choose to have more”. Oral chemotherapies are more convenient, can give a patient a greater sense of autonomy and save hospitals money.

### **Medical experts agree the system needs improving**

“It is essential that the benefits system keeps up to date with the medical profession and doesn’t treat people differently because of the type of cancer treatment they receive”. **Prof Jane Maher, Chief Medical Officer, Macmillan Cancer Support**

“The current rules for automatic entitlement to ESA...may need to be changed to include cancer patients going through other forms of treatment such as oral chemotherapy and radiotherapy which can sometimes be equally as debilitating.”  
**Prof Harrington, Independent Reviewer of the Work Capability Assessment**

## **2. The majority of people with cancer need ESA for longer than 12 months**

*Macmillan believes that people with cancer who have worked and paid into the system before becoming ill should be supported without their ESA being means-tested.*

The Government proposes to limit the length of time someone allocated to the ESA Work-Related Activity Group can receive the benefit, without being means-tested, to 12 months. The thresholds for means-testing are such that someone who has not been able to return to work after 12 months, who has a partner who earns just £149 per week or works for more than 24 hours per week, will lose all of their weekly ESA.

The vast majority of people with cancer who are out of work because of their condition want to work. Getting back to work is a crucial step forward in getting their lives back after cancer. But evidence shows that the majority of people with cancer claiming ESA take much longer than 12 months to return to work:

- Three quarters (75%) of people with cancer placed in the ESA Work-Related Activity Group are still claiming ESA 12 months later
- Almost two thirds (61%) still need the benefit 18 months after first claiming it
- Just 13% of people with cancer find work within one year of starting the current back to work support programme ‘Pathways to Work’.

## Why do cancer patients generally take longer than 12 months to get back to work?

People with cancer face a range of barriers that impact on their ability to return to work:

- They can experience debilitating physical and psychological effects from cancer and its treatment, including severe pain, fatigue, nausea, fever and diarrhoea
- The majority (53%) are not advised by medical professionals about the impact of their cancer diagnosis on their working life and how they can manage their condition
- They are not routinely offered the range of back to work services they need such as counselling, re-training and work-placed advocacy
- They are less successful in securing workplace adjustments that they are legally entitled to, which help them return to work. This is likely linked to the fact that just 43% employers know that people with cancer have legal protection against discrimination.

*"My cancer has spread to my bones and I'm told it is incurable. I've had surgery and radiotherapy but have been told that to get ESA now I've got to do job focussed interviews to help get me back into work. I don't need a work ethic, I've had one all my life. I'm still in constant pain and feel tired all the time. I've paid into the system all my working life but the Government seems to expect me to be fit after a year, and if I'm not, take away my support."* **Chris, diagnosed with lung cancer, Worcester**

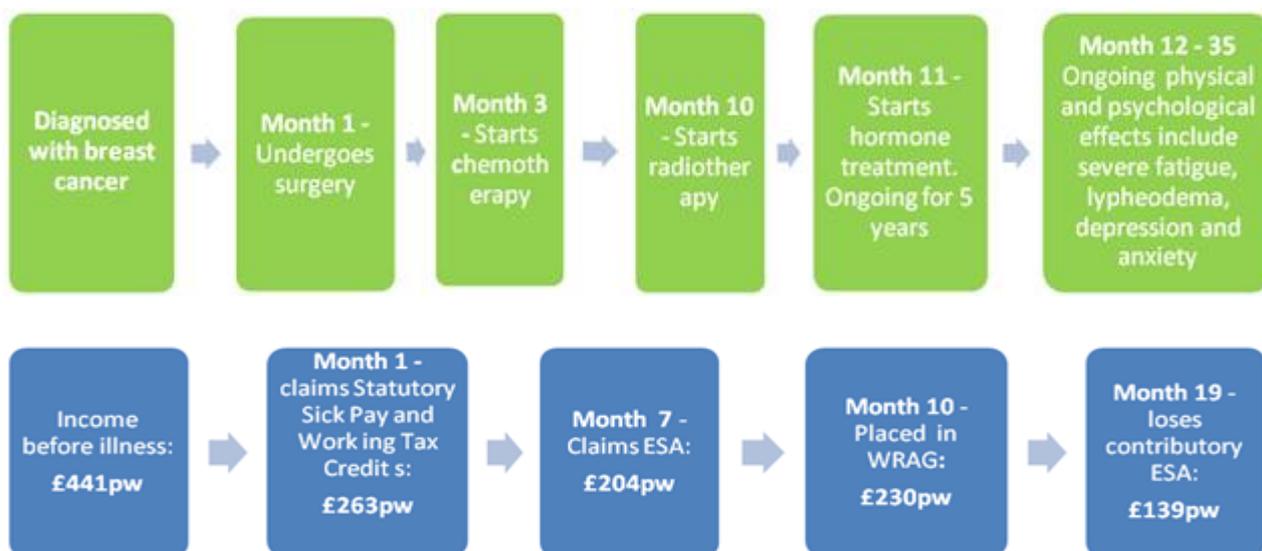
## The impact of time-limiting on people with cancer

The proposed changes will be very rapid – time-limiting will start from April 2012.

Anyone in the ESA Work Related Activity Group from April 2011 will, if they exceed the means testing threshold, immediately lose £91 a week. Some people with cancer who are just about coping financially will be dumped straight into poverty.

### **An example where a couple's disposable income drops 68% from £441 to £139:**

*Paul and Anne are in their late fifties. After a breast cancer diagnosis Anne starts treatment and claims Statutory Sick Pay (SSP). When means-tested for ESA after 12 months, Paul and Anne stop receiving any money as Paul works more than 24 hours per week. Anne experiences physical and psychological effects long after treatment has ended which mean she is not 'fit for work' after 12 months.*



### 3. DLA reform must take into account the specific needs of people with cancer

*Macmillan believes that people should be able to apply for support with the costs associated with their long term condition as soon as these support needs arise.*

The Personal Independence Payment (PIP), which will replace Disability Living Allowance (DLA), is for those with support needs associated with long term disability or illness. The Government proposes that someone must demonstrate they need this benefit for six months, instead of the current three months, before they can even be assessed for PIP. Cancer treatment, and its debilitating effects, can begin very quickly after diagnosis. The associated support needs are often immediate.

Importantly, the first three to six months is often the period when extra costs are greatest, just as people are trying to adjust their outgoings to their reduced income.

#### What support needs do people with cancer have in the first six months?

- **Travel and parking costs** for hospital appointments – low immunity often forces people to rely on taxis rather than use public transport. Bengu's old work colleagues put £300 in her bank to help cover the cost of taxis. Not everyone is fortunate enough to have this sort of support
- **New clothes** – many people experience dramatic weight loss or gain. One cancer patient said "some clothes hurt my chest if I wear them...I wear t-shirts or pullovers instead, even on the occasions I'm wearing a sari"
- **Extra fuel costs** – increased need for heating, and increased use of the washing machine due to profuse sweating and hygiene requirements.
- **Aids, adaptations, wigs, shoe inserts, special diets**

*"I used DLA to pay for my increased food and travel costs, and dietary supplements – about £50 per week. On top of that I was using extra heating – one quarter I had an electricity bill of £400! Treble my norm. This made me very stressed. I was mentally exhausted. I couldn't pay the bills; debtors were harassing me on the phone and by post, threatening to repossess my house". **Liz, diagnosed with breast cancer, Belfast***

Macmillan believes people should be able to be assessed for PIP as soon as their needs arise. The new assessment process, which must be designed to capture the needs of people with cancer, will ensure that only those eligible will receive PIP. Periodic reviews will make sure that people receive PIP only for as long as they need it.

#### Suggested questions to be posed during the second reading debate

- Will the Government give assurances that people receiving oral chemotherapy or radiotherapy will not be forced to undertake a medical assessment to determine their eligibility for ESA or be forced to engage in work related activity?
- Will the Government guarantee that people who not 'fit for work' will continue to receive ESA until they are ready to return to work?
- Will the Government recognise that people with long term conditions who face immediate additional costs because of their disability should get support to help with these costs at the point of need?

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