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Welfare Reform Bill

Bill Number: Bill 13/11-15

Dear Members of the Committee

In 2008 I was diagnosed with Chronic Lymphocytic Leukaemia (an incurable blood cancer). My condition is progressive and incurable. Last year I underwent a course of chemotherapy. The treatment is palliative and I will require further chemotherapy at some stage.

In 2009 I was diagnosed with Transitional Cell Carcinoma of the renal pelvis and underwent a nephroureterectomy (removal of right kidney, ureter and excision of bladder cuff).

I accepted medical retirement in 2011 after many years working in the media and in local government. I receive DLA and ESA. In addition to a small occupational pension. As a person living with cancer and struggling financially as well as emotionally, due to the condition, I would like to ask the Committee to consider how the proposed adoption of certain clauses of the Welfare Reform Bill will affect those of us facing the daily challenge of living with this devastating illness.

Personal Independence Payment (Part 4)

Disability Living Allowance has been a huge part of increasing equality for disabled people. It has been our means of working around the problems of a disabling world, our means of, at least partially leveling the playing field and *doing it ourselves* - not relying on charities or government organisations to determine exactly what we need in the way of transport or help at home. I believe that the introduction of Personal Independence Payments threaten this for a great number of people.

People with cancer, and the parents of children with cancer, are very worried about how the Welfare Reform Bill will affect them. Living with cancer is expensive and many people rely on benefits to make ends meet. I hope you will ensure that your reform of the welfare system works for people with cancer, so that cancer patients receive the support they need when they need it the most.

Clause 77 - Daily Living Component

I am concerned about the levels at which the rates for the daily living components will be set; many cancer patients will lose out because of the reduction from three to two rates.

If simply the lower rate of care is removed it will be cancer patients who need help for part of the day and help with cooking who are most likely to lose out. In these circumstances financial support provided by the lower care rate is often used to retain independence by, for example, paying for online deliveries, cleaners, pre-prepared vegetables, microwaves etc.

Removing the lower rate care component would have a particular impact on, for example, breast cancer patients who have had the lymph nodes removed and as a result experience restricted arm movement or cancer patients who continue to experience severe fatigue and have difficulty doing many tasks, such as many patients with cancer of the head and neck. As well as the direct financial support provided by DLA, removing lower rate care will also mean that many cancer patients will lose related passported benefits.

As a result of treatment cancer patients often experience a sudden onset of daily living and/or mobility needs that can result in significant additional costs that are often long-term. Thousands of cancer patients rely on DLA to help meet these costs at a time when their income has often decreased significantly. Without this support we fear that many cancer patients will be unable to meet the additional costs of living with their condition, which will exacerbate existing issues that contribute to cancer poverty.

Currently, there are two million people living with and beyond cancer in UK and this figure is rising by three per cent each year. As cancer survival rates continue to improve, people diagnosed with cancer will increasingly join people with other long term conditions in living with ongoing support needs. Some people living with and beyond cancer have serious physical, emotional, social problems that need addressing. As a result of these reforms it seems inevitable that thousands of cancer patients who are living with additional costs as a result of their conditions will be left without the crucial financial support that is currently offered by DLA.

Gateway Benefits

I wish to express my unease and deep concerns over people losing passported benefits as a result of UK wide changes in the wake of this legislation. DLA is a Gateway Benefit. For example, if you are in receipt of the middle or higher rate Care Component of DLA, then a partner, friend or family member who is unable to work full time because of their caring responsibilities may be able to claim Carer's Allowance. Receiving some rates of DLA can mean VAT exemption on some essential equipment. If you are in receipt of the higher rate Mobility Component of DLA, you are eligible for a Blue Badge. There is a very real danger that many disabled people will lose out on the important gateway aspects of DLA which help to make their difficult lives more bearable.

Fluctuating conditions

I believe it is crucial to ensure that those carrying out the PIP assessment consider how a person's condition fluctuates over the course of a day. We know that due to severe fatigue that can result from cancer treatment many cancer patients' ability to carry out everyday tasks will change dramatically over the course of a day. For instance, a cancer patient who is able to prepare a meal in the morning may be unable to prepare a meal in the evening.

With regards to applicants who are awaiting treatment the technical briefing note states that the descriptor choice will be based on the *"likely continuing impact of the health condition or impairment as if any treatment or further intervention has not occurred"*. Although I understand the difficulties in predicting the likely impact of

treatment this approach could be particularly problematic for cancer patients, who often experience significant debilitation as a result of their treatment. Unless their situation is reviewed following the start of treatment it is likely that their real needs will not be captured accurately and they may not receive the rate of PIP that they are entitled to.

Employment and Support Allowance (ESA) Chapter 2

I was dismayed at the Government's decision to overturn a Lords' amendment that would protect sick and disabled people including cancer patients from losing a vital out of work benefit – Employment and Support Allowance (ESA) - after 12 months. Ciarán Devane, Chief Executive of Macmillan Cancer Support, said:

*“We are bitterly disappointed on behalf of the thousands of cancer patients that the Government has today failed to protect. They will now be forced to bear the brunt of the economic crisis. **“Despite mass opposition from Lords, the public, their own supporters and the whole cancer community, the Government has pushed through an unfair proposal which means thousands of cancer patients – still recovering from their illness and therefore too sick to work - will see their income drop by up to £94 a week from April.”***

I urge the Committee to give close consideration to the additional hardship the imposition of such a time limit will have on people in Northern Ireland who live with cancer. A diagnosis of Cancer is devastating emotionally, physically and financially. I implore the Committee to work with bodies like Macmillan Cancer Support and pay attention to its concerns on welfare reform.

Yours faithfully

Gary Hunter

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