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*Jeane Clare*

In view of the Committee's forthcoming consideration of proposed amendments to the Social Security (Scotland) Bill concerning the definition of "terminal illness", I thought it might be helpful to inform the Committee that I have written to the Chief Medical Officer for Scotland and number of a number of medical organisations to seek their views on this issue. A copy of the letter is attached.

You will note that it has issued to:

General Medical Council (Scotland)  
General Medical Council (UK)  
Academy of Royal Medical Colleges and Faculties in Scotland  
BMA Scotland  
Medical Defence Union UK  
Medical Protection Society UK (covers Scotland)  
Medical Defence for Doctors and Dentists in Scotland  
Royal College of Nursing, Director of the Royal College of Nursing (Scotland)

In keeping with our principles that our social security system should be based on treating people with dignity and respect, I am fully committed to ensuring that people who are terminally ill should receive the support to which they are entitled as quickly as possible.

I have already committed to as a minimum replicating the current special rules and fast-tracking for individuals applying for Disability Assistance. However, there is at present no consensus on how we might define terminal illness and, in keeping with our commitment to co-design and consultation, I consider it essential to seek the views of the medical profession, before setting out any such definition in law. I have therefore written to a number of medical professional bodies to seek their views.

You will note that I have asked for responses by 30 March to allow me to put forward any necessary amendments at Stage 3.

I hope the Committee will find this information helpful, ahead our discussion later today.

Kind regards



**JEANE FREEMAN**

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5 February 2018

Dear Colleague

As you will be aware, historic legislation to establish Scotland's first social security system was introduced to the Scottish Parliament on 21 June 2017.

The Social Security (Scotland) Bill (the Bill) will give the Scottish Government the powers to deliver eleven benefits devolved as part of the Scotland Act 2016 and is a significant moment for Scotland and for the history of devolution. This gives our Government and this Parliament the opportunity to make different choices – and shows that we can create a fairer and more just society when we take matters into our own hands.

I am writing to you because during the course of the Bill's progress, amendments have been tabled that seek to change the current special rules associated with terminal illness set out in the Social Security Contributions and Benefits Act 1992 (e.g. DS 1500), which covers the UK.

At present, the Bill before our Scottish Parliament provides for disability assistance regulations to define what "terminal illness" means, for the purpose of determining entitlement to disability assistance. This offers the potential to extend the definition of who is terminally ill for the purposes of assistance. It also allows for persons who are terminally ill to be fast-tracked onto assistance.

As you will know, the current definition of terminal illness used by the Department for Work and Pensions is that a person is terminally ill '*if the person suffers from a progressive disease and the person's death in consequence of that disease can **reasonably be expected within 6 months***'. It provides that if a person only has a short time to live (up to 6 months); they should be fast-tracked through the benefit system without the usual tests relating to disability. Those that are terminally ill, but with a longer predicted life-span, are not eligible for fast-tracking, but they can still apply for disability benefits through the usual routes. The alternative suggested definitions are:

### **General Medical Council – 'approaching the end of life'**

The General Medical Council currently set outs the following definition of "approaching the end of life";

*"Advanced, progressive, with indicators of deterioration, and where death will be an inevitable consequence of the condition [and likely to die within 12 months]"*

Guidance from the General Medical Council includes:

- Advanced, progressive, incurable conditions;
- General frailty and co-existing conditions that mean they are expected to die within 12 months;
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition; and
- Life-threatening acute conditions caused by sudden catastrophic events.

We understand that this guidance has been produced to assist clinicians to make decisions about treatment and care that support individuals to live as well as possible until they die, and to die with dignity. The guidance advises that patients are 'approaching the end of life' **when they are likely to die within the next 12 months.**

It has also been suggested that this definition could be used without the time restriction, meaning there would be **no requirement to consider whether the patient is likely to die within 12 months.**

### **The existing rule with an extended time restriction**

The amendments that have been lodged to the Bill seek to retain the current DWP definition of terminal illness which states that '*the person suffers from a progressive disease*'. However we could amend the time restriction from '*the person's death in consequence of that disease can reasonably be expected within 6 months*' to '*the person's death in consequence of that disease can reasonably be expected within 2 years*'.

## Your view

I am acutely aware that this is a clinically complex area and that it will remain the role of medical professionals and some specialist clinical staff to decide whether an individual meets the criteria of 'terminal' to be fast-tracked for disability benefits when responsibility for these transfers to Scotland.

I also understand that decisions on such eligibility can involve very difficult conversations with individuals and their families or representatives. On this basis, I would be very grateful for your opinion on the proposed changes to the definition and time restriction for terminal illness.

From your experience, I would appreciate your view on what you think is a suitable definition for terminal illness.

I am anxious to understand how the rules will impact on the complexity and consistency of decision making, and how any change in definition might interact with the definition used by the Department of Work and Pensions, given that their definition will remain in place for benefits that remain reserved to the UK Government.

The next opportunity I will have to propose any amendments to the current provisions for terminal illness will be at Stage 3 of the Bill in April. I would therefore be grateful to have your views and any comments you may wish to offer by **30 March 2018**.

I believe strongly that everyone has a right to social security and I want to make choices that work for Scotland, reinstating fairness into the social security system and listening to key individuals and organisations that can help to shape this.

Kind regards



**JEANE FREEMAN**