29 July 2020

Dear Minister,

Re: Scrap the 6 month rule for terminally ill welfare claimants

On behalf of the organisations undersigned, we are writing to urge you to scrap the cruel six month rule which determines eligibility for fast-track welfare support for terminally ill people.

Among our organisations are health charities which provide care and support for people with terminal illnesses, representatives of the advice sector and other experts. We have seen first-hand the devastating impact that a terminal diagnosis can have, and how much more difficult that situation becomes when dying people face additional barriers to accessing the financial support they are entitled to.

The Special Rules for Terminal Illness are meant to help people get the support they need quickly and with as little bureaucratic interference as possible – allowing them to enjoy a better quality of life during the time they have left. Unfortunately, too many people with unpredictable conditions like motor neurone disease, COPD and chronic heart failure are falling through the cracks, and are forced to endure long delays, distressing assessments and extensive paperwork to access their welfare payments.

Marie Curie and the Motor Neurone Disease Association have been calling for the six month rule to be scrapped and replaced with a system based on clinical judgement, as has been adopted in the Social Security (Scotland) Act 2018. Under the Scottish system, it will be up to a claimant’s GP, consultant or other clinical professional to determine if they are terminally ill for the purpose of applying for fast-track welfare support.

This is a much fairer and more compassionate system. If similar changes were introduced in Northern Ireland, it would ensure many more terminally ill people are able to access the financial support they need, when they need it.

Evidence around the need for change has been growing for some time. In 2018, Walter Rader’s independent review of the Personal Independence Payment assessment process recommended that the six month rule be replaced with a clinical judgement-based system. In the opinion of Mr Rader, “this will lessen pressure, stress and anxiety on claimants and their families at what is an already difficult time.” [1]

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A year later, an inquiry by the All Party Parliamentary Group for Terminal Illness in Westminster concluded that the six month rule is “unfit for purpose, outdated, arbitrary and not based on clinical reality.” [2]

Most recently, Belfast High Court ruled on 8 July 2020 that the difference in treatment for terminally ill welfare claimants who cannot reasonably meet the six month life expectancy criterion is discriminatory. In his robust ruling, Mr Justice McAlinden said that this difference in treatment was “manifestly without reasonable foundation.” [3]

It is also important to recognise that this call for change has local cross-party support. On 3 July 2019, representatives of the DUP, Sinn Féin, SDLP, UUP, Alliance Party, Green Party and People Before Profit issued a joint demand for reform of the Special Rules, labelling the current system as “cruel” and “inhumane”. [4]

You will be aware that the Department for Work and Pensions announced a UK-wide review into how the welfare system supports terminally ill people in July 2019. This review is incredibly important, but more than a year has passed since it was launched and a date is yet to be set for the publication of its findings. Dying people in Northern Ireland simply do not have any more time to lose before the system is reformed.

Our organisations believe the case for scrapping the six month rule is irrefutable. We are calling on the Department for Communities to recognise the weight of evidence outlined above and legislate to scrap the six month rule without delay.

We would welcome the opportunity to meet with you to discuss these issues further. If you require any additional information please do not hesitate to contact us at the address above.

Yours sincerely

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Marie Curie Northern Ireland

Craig Harrison
Policy and Public Affairs Manager
Marie Curie Northern Ireland

Creea Convery
Service Development Manager
Motor Neurone Disease Association NI

Ursula O'Hare
Director
Law Centre NI

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4 ‘Stormont parties demand fairer benefits system for terminally ill people’, 03.07.19.
Gavin Adams  
Director, Business Development  
Extern NI

Suleiman Adbulahi  
Director/Founder  
Horn of Africa People's Aid Northern Ireland

Geraldine Alexander  
Assistant Secretary (Equality and Human Rights)  
NIPSA

Pat Austin  
Director  
NEA Northern Ireland

Tara Collins  
Programme Manager  
Dementia NI

Liz Cuddy  
Chief Executive  
Southern Area Hospice Services

Genevieve Edwards  
Chief Executive  
Bowel Cancer UK

Carolyn Ewart  
National Director  
BASW Northern Ireland
Joanne Farrell
Welfare Rights Manager
Belfast Unemployed Resource Centre

Paul Finnegan
Director
Cruse Bereavement Care Northern Ireland

David Galloway
Northern Ireland Director
MS Society

Kevin Higgins
Head of Policy
Advice NI

Susan Irvine Russam MBE
Chief Executive
GEMS NI

Olwen Lyner
Chief Executive
NIACRO

Clare-Anne Magee
Head of Carers NI

Bernadette McAliskey
Chief Executive
STEP

Paschal McKeown
Charity Director
Age NI
Fearghal McKinney
Head of Northern Ireland
British Heart Foundation

Anne McVicker
Director
Women’s Resource and Development Agency

Rachel Powell
Women’s Sector Lobbyist
Women’s Resource and Development Agency

Laura O’Dowd
Director of House
Ark Housing Association

Sandra Peake
Chief Executive
WAVE Trauma Centre

Heather Weir
Chief Executive
NI Hospice