

13 March 2024

Dear Committee Chair

RE: Marie Curie comments Legislative Consent Motion (LCM) on Pensions (Special Rules for End of Life) Bill 2024.

Thank you for your correspondence dated 8 March 2024 seeking Marie Curie's views on the Legislative Consent Motion (LCM) on Pensions (Special Rules for End of Life) Bill 2024.

We understand that this Bill intends to amend existing legislation covering the Pension Protection Fund (PPF) and Financial Assistance Scheme (FAS) definition of terminal illness, so that people with a life expectancy of up to twelve months (instead of six months) can receive terminal illness payments. We also understand that this change would only apply to those schemes 'where the sponsoring employer became insolvent on or after 6 April 2005 and the scheme has insufficient assets to secure its pension liabilities at least to the level of compensation that would be payable by the PPF.'

Whilst the narrow scope of this Pensions (Special Rules for End of Life) Bill 2024 means the change is likely to impact a small number of people with a terminal illness, more generally the focus on private pension schemes and their response to members with a terminal illness is welcome. The financial support provided by payouts from private pensions or life insurance policies can be critical for working-age people who are diagnosed with terminal illnesses.

Marie Curie and the Motor Neurone Disease Association campaigned passionately to improve access to social security payments for those with a terminal illness through the 'Scrap 6 Months' campaign which led to the Social Security (Special Rules for End of Life) Act 2022. The definition change for terminal illness is a step in the right direction and we welcome its adoption within the PPF legislation and the FAS regulations. Furthermore, we would welcome universal application of this new definition across all private pension schemes.

However, as was argued during the 'Scrap 6 months' campaign an arbitrary timeframe around expected life expectancy does not address the broader issue around the unpredictable nature of many terminal conditions which can make the 'burden of proof' required by schemes with respect to life-expectancy difficult or impossible to meet.¹ This can leave dying people unable to access the financial support they need until it is too

¹ [all-party-parliamentary-group-for-terminal-illness-report-2019.pdf \(mariecurie.org.uk\)](#)

late, plunging them and their loved ones into a position of poverty. The preference would be for pension and life insurance providers to ensure all working age terminally ill people can easily access the financial support they need from their policies, regardless of prognosis.

We would like to take this opportunity to draw the Committee's attention to the other significant reforms Marie Curie is calling for with regards to the State Pension. Whilst there can be practical / process issues with individuals securing early access to private pension cover, it must be acknowledged that many private pension schemes do routinely allow early access to pension funds on grounds of illness / terminal illness. This is currently not the case for the State Pension- recent research commissioned by Marie Curie has found that those of working-age are twice as likely to fall into poverty on diagnosis of a terminal illness compared to those claiming their State Pension. Forced to quit work just as their expenses skyrocket, more than one in seven people in Northern Ireland will spend their final days in poverty. The State Pension is meant to be there for us when we retire, however, if you're unfortunate enough to become medically unfit to work before 65, you miss out – even if you've paid into the system your whole working life. All working-age people diagnosed with a terminal condition should be given early access to their State Pension.² A cost benefit analysis of such a UK wide policy change indicates this would have a minimal cost to the public purse. A means-tested approach, for example, would cost the UK Government 0.1% of its annual spend on the State Pension.³

Thank you for seeking our comments on this Legislative Consent Motion and the opportunity to draw attention to the broader work Marie Curie is doing in Northern Ireland to highlight financial insecurity for those with a terminal illness- we would welcome further engagement with the Committee on this matter and the solutions to better support these extremely vulnerable people and their families.

Yours Sincerely



Joan McEwan
Associate Director Policy and Public Affairs

² Dying in poverty: Examining poverty at the end of life in the UK- Implications for Northern Ireland, Centre for Research in Social Policy, Loughborough University.

³ Policy interventions to alleviate poverty at the end of life – a cost/benefit analysis, Centre for Research in Social Policy, Loughborough University.

Sent: 14 March 2024 16:06

Subject: RE: Legislative Consent Motion (LCM) on Pensions (Special Rules for End of Life) Bill 2024

Hi Sean,

Further Information to Inform Committees communication with Westminster on this Bill.

My Marie Curie policy colleague in English has mentioned potentially trying to get an amendment on the Bill during Westminster Committee stage- my understanding is that this amendment would be to extend the Bill to all 'Pension Protection Fund' pension schemes across the UK and not just those that become insolvent. Expansion of the Bill in this way would align it with the DWP guidance for pension fund providers which is 12 mths and would ensure all schemes adhere to this good practice. [Early retirement, your pension and benefits: Personal and workplace pensions - GOV.UK \(www.gov.uk\)](https://www.gov.uk/early-retirement-your-pension-and-benefits)

The Committee may wish to consider making this recommendation / suggestion in its response to Westminster / Laurence Roberston MP.

Regards

Christine