

Policy note: Guaranteeing a State Pension-level income to people living with a terminal illness

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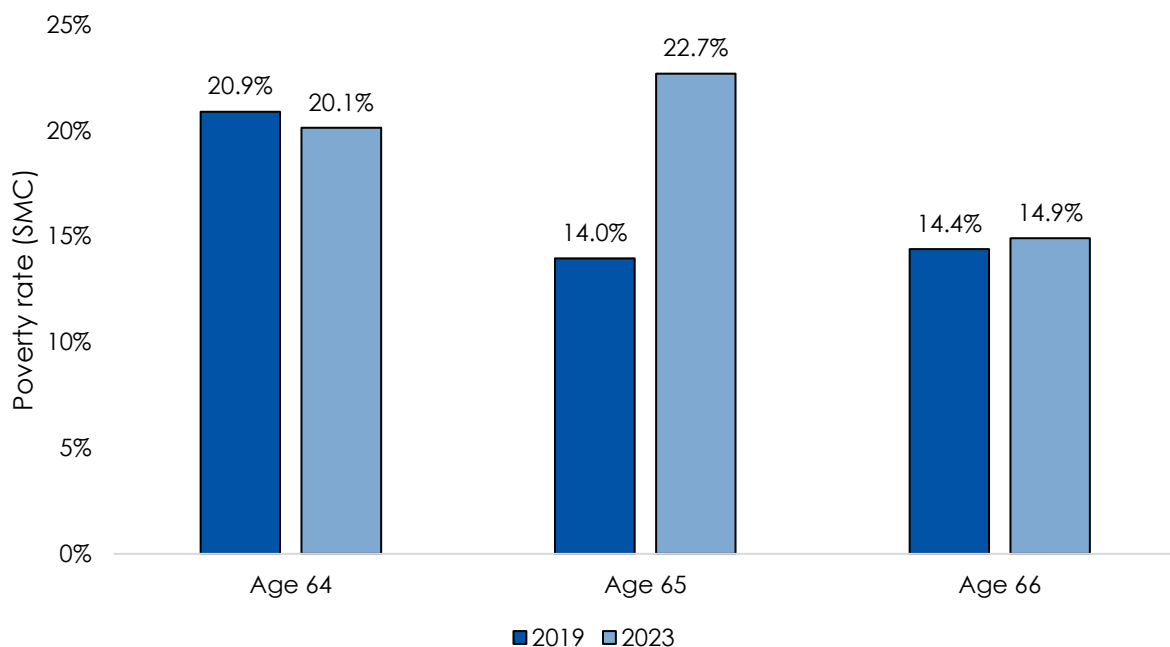
November 2024

1. Introduction

More than 1 in 4 people who die in working age spend the last 12 months of their lives in poverty – a much higher risk of dying in poverty than people who die in pension age.

Marie Curie's research has shown that the State Pension is a far more effective safeguard against poverty than the working-age benefit system. This is most clearly shown by comparing rates of deaths in poverty between people aged 65 in 2019 (who would have reached the State Pension Age) and people aged 65 in 2023 (who had not, as the State Pension Age had risen to 66):

Estimated proportion of people aged 64-66 in poverty in the UK in 2019 and 2023, by single year of age



Source: Family Resources Survey (DWP)

It isn't right that people living with a terminal illness are forced to spend their final months, weeks, and days worrying about how to put food on the table or afford their energy bills, rather than focusing on what really matters. This just causes unnecessary additional stress to them and their families.

Marie Curie's #CostOfDyingCrisis campaign calls upon the UK Government to guarantee a State Pension-level income for anyone of working age, with less than 12 months to live. The remainder of this note sets out one possible route to achieving this.

2. Providing access to the State Pension and introducing a Pension Credit Element to Universal Credit

Access to the State Pension

There are several ways to achieve a State Pension-level of income for working-age people living with a terminal illness, but we think that by far the simplest way is to use the existing State Pension system.

There is currently no way to receive the State Pension before someone reaches State Pension Age. However, it is common for private pension schemes to allow early access on medical grounds if someone is diagnosed with a terminal condition, and government recognises this by allowing the entire pension pot to be taken as a tax-free lump sum (rather than just 25%), and to be taken before the age of 55 with no tax penalty. However, there is no comparable recognition for the State Pension.

We propose, as a first step, that working-age people with less than 12 months to live should receive State Pension payments based on their National Insurance Contribution record to date – effectively treating them as though they were of State Pension Age now. This group could be identified through the same route as the Department for Work and Pensions currently uses to determine eligibility for the Special Rules for disability benefits.

That would mean that anyone of working age with between 10 and 35 years of contributions would receive some amount of State Pension, and anyone with over 35 years of contributions would receive the full New State Pension (currently £221.20 a week). This reflects that their entitlement to the State Pension had built up, but that they are not expected to live until State Pension Age.

Previous reviews of the State Pension

Neither the 2017 Cridland Review¹ nor the 2022 Neville-Rolfe Review² of the State Pension considered specifically extending State Pension access to people living with terminal illness, but they did consider the general possibility of varying the State Pension Age for some groups.

The Cridland Review concluded that “there is no effective mechanism that has been tested that would be able to target those with lower life expectancy, and in such a way that people could be given fair warning of their State Pension outcomes”.

¹ <https://www.gov.uk/government/publications/state-pension-age-independent-review-final-report>

² <https://www.gov.uk/government/publications/state-pension-age-independent-review-2022-final-report>

However, when it comes to people living with a terminal illness, there is a clear and effective mechanism available to target people: the submission of an SR1 form, to provide access under the Special Rules for people with less than twelve months to live. This objection therefore doesn't apply to our proposal.

The Neville-Rolfe Review, meanwhile, recommended "that the Government explores the possibility of an early access scheme whereby workers who meet certain qualifying criteria can access their State Pension early at an actuarially reduced rate. This could include individuals aged, say, 65 and above and with 45 years of National Insurance contributions or equivalent and should aim to help those who have performed physically demanding roles over many years".

Again, while it could be challenging to define the 'physically demanding roles' this approach envisages, that does not apply to our proposal, as the need to identify people likely to have less than 12 months to live is already established within the benefits system. And Baroness Neville-Rolfe's proposal does recognise a core principle behind our proposal - that it is unjust for people who have paid into the system for decades to be denied the benefit that the State Pension system provides, simply because they die too soon.

Neither of these reviews present any substantial objections to our proposals: they did not specifically consider providing early access to people living with a terminal condition, and the wider objections or challenges around accurate identification of people who could be eligible for early access are easily resolved by our proposal, which uses existing parts of the benefits system. The remaining issue may be related to cost, which we discuss later in this note.

A Pension Credit Element in Universal Credit

Analysis conducted on behalf of Marie Curie³ suggests that, if early access to the State Pension was introduced, around a quarter of working-age people with less than 12 months to live would receive the full State Pension. Many, however, would not have the full years of National Insurance contributions, for example if they moved to the United Kingdom during their working life, or are simply too young to have accrued that level of contribution before being diagnosed with a terminal condition.

Of those who wouldn't receive the full State Pension, some will have other sources of household income to insulate them from the effects of poverty. But others will rely solely on the benefits system. If they were over State Pension Age in the same circumstance, this group would benefit from Pension Credit to top up their income – the same guarantee could be provided to working-age people living with a terminal condition by introducing a Pension Credit Element in Universal Credit (UC). We would suggest that this is paid instead of the Limited Capability for Work and Work Related Activity (LCWRA) element of UC, and is set at a rate equivalent to

³ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/policy-interventions-to-alleviate-poverty-at-the-end-of-life.pdf>

the single or couple component of PC, minus the UC standard allowance (25 or over rate). At 2024/25 rates this would be:

Single: £218.15 – £91.80 = £126.35 a week

Couple: £332.95 – £142.52 = £190.43 a week

An additional £81.50 'severe disability addition' would be payable where the terminally ill claimant meets the conditions for the Severe Disability Addition in Pension Credit.

This approach would allow people who are diagnosed with a terminal illness when of working age to benefit from the entitlement they've built up throughout their working lives by receiving the State Pension. It would also ensure that those most likely to fall below the poverty line after a terminal diagnosis – those with a lower NIC record and those without significant savings or assets, who would be reliant on benefits as their sole or main source of income – would have a guaranteed minimum income.

3. How this solution would interact with other benefits

In many cases, people living with terminal illness will be claiming other benefits such as Personal Independence Payment (PIP), contribution-based Employment & Support Allowance (New Style ESA), and Universal Credit (UC).

Our intention is that most working-age people living with a terminal condition who have built up a significant NIC record, or are on a low income, are significantly better off. We also want to ensure that no-one would be worse off as a result of this proposal.

Therefore, we propose that this approach would interact with other benefits in the following ways:

Universal Credit: There are already circumstances where the State Pension might interact with a Universal Credit award. A couple might receive both the State Pension and Universal Credit if one of the couple is over State Pension Age and one is under.

In these circumstances, the State Pension is treated as 'unearned income', and deducted pound-for-pound from the UC entitlement. We propose that this should remain be the general approach to a household receiving Universal Credit in which the State Pension is paid to one of the claimants.

We also propose introducing a new 'Pension Credit element' in Universal Credit for people with less than 12 months to live who are now receiving the State Pension. This would ensure that someone's Universal Credit entitlement is increased to at least the level that would be received through the Pension Credit guarantee.

Personal Independence Payment: Normally, pensioners are unable to claim Personal Independence Payment (PIP). Instead, they can claim Attendance Allowance (AA). AA is paid at the same rate as the highest daily living amount of PIP. PIP may also include a mobility component (of up to £64.50) which many terminally ill people are entitled to and would not wish to lose out on.

In practice, eligibility for PIP (as opposed to AA) is based on the claimant not having reached State Pension Age. While our proposal would entitle terminally ill claimants to access their State Pension early, they have not reached State Pension Age and so we propose their entitlement to PIP remain unchanged.

As PIP is a non-means-tested benefit, receipt of the State Pension would not affect PIP entitlement.

New style Employment & Support Allowance: A person may claim New Style ESA (ns-ESA) if they have recently made National Insurance contributions. It can be claimed on its own or in addition to UC, and it is not affected by savings or most income.

In some cases, someone's ns-ESA entitlement may exceed their State Pension entitlement. So if they had to claim the State Pension instead of ns-ESA they could be left worse off.⁴

One option to deal with this would be to allow someone to claim either the State Pension or ns-ESA, but not both. The risk with this is that people would need to calculate which is best to claim, and in some instances make the wrong decision and be worse off as a result.

Instead, we propose enabling people to claim both ns-ESA and the State Pension if they choose to, but to treat them as overlapping benefits. This removes the need for the person living with a terminal illness to work out the best approach. Any State Pension received would be deducted from the ns-ESA entitlement, which may reduce that entitlement to zero.

⁴ This would not be the case if they were receiving UC, as their overall level of income would be set by UC entitlement, rather than either SP or ESA rates.

4. Impact and cost

Impact on poverty

In June 2022 Marie Curie asked Loughborough University to model the cost and benefits⁵ of extending access to the State Pension to anybody who meets the new definition of terminal illness in the UK benefits system introduced by the DWP in the Social Security (Special Rules for End of Life) Act 2022, namely that their death can be “reasonably expected within 12 months.”

According to that analysis, based on figures from the analysis conducted in 2022, adopting this policy would lift around 8,600 people in working age out of poverty in their last year of life each year, and reduce the poverty rate among working age people with a terminal illness from 26% to just 14% - in line with the rate of end of life poverty among pensioners (see table 1 below).

This policy would have eliminated the additional risk of poverty at the end of life currently experienced by people of working age living with a terminal illness.

Table 1: Cost/benefit analysis of extending State Pension to people aged 20-64 in the last 12 months of life

	No intervention (current policy)	Proposed policy
Poverty rate for those in last year of life (%)	26.0	14.1
Number in poverty (thousands)	18.9	10.3
Number lifted out of poverty (thousands)	-	8.6
Weekly cost to the state (£millions)	-	2.2

Source: Loughborough University analysis conducted on behalf of Marie Curie

How much would this cost the UK Government?

As indicated in the table above, according to Loughborough University’s analysis the cost of extending the State Pension to working-age people with a terminal illness as described would be £2.2 million per week – or £114.4 million per year.

To put this figure into context, in 2021-22 the total UK State Pension bill was £104.7 billion; extending the State Pension to terminally ill people in working age and lifting 8,600 people out of poverty at the end of life would therefore cost the UK Government an additional 0.1% of the annual State Pension bill.

We have not repeated this analysis based on the figures in our 2024 report, but the costs and benefits are likely to be of a similar scale. As the population ages, the cost of this policy as a proportion of the total cost of the State Pension is also likely to become even smaller over time, as there will be more pensioners for every working-age person than there are today.

⁵ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/policy-interventions-to-alleviate-poverty-at-the-end-of-life.pdf>

5. Worked examples

In all of the examples given below, amounts are given per week and rounded to the nearest £1 for simplicity. They all apply to someone living with a terminal illness who is expected to have less than 12 months to live.

Example 1: Pradeep

Pradeep is 55 years old, with one child, and rent of £100 per week. She has no other income or savings. She has an underlying State Pension entitlement of £150 per week. She receives the daily living component of PIP at the enhanced rate.

Current entitlement

Benefit	Amount
New-Style ESA	£138
Universal Credit	£215
Standard Allowance	£91
Child Element	£66
Housing Element	£100
LCWRA Element	£96
Reduction due to New-Style ESA	-£138
PIP	£109
Total	£462

Entitlement following changes

Benefit	Amount
New-Style ESA	£0
Initial entitlement	£138
Reduction due to State Pension	-£138
State Pension	£150
Universal Credit	£315
Standard Allowance	£91
Child Element	£66
Housing Element	£100
Reduction due to State Pension	-£150
Pension Credit Element (instead of LCWRA element, including severe disability addition, with the Standard Allowance amount deducted)	£208
PIP	£109
Total	£574

Pradeep's income is increased by £112 per week following the extension of the State Pension, and the addition of the pension credit element to Universal Credit.

Example 2: John and Amy

John is 60. He has an underlying state pension entitlement of £50 per week, he is entitled to ns-ESA. He receives the daily living component of PIP at the enhanced rate. His partner Amy earns £40k per annum. They have no children.

Current entitlement

Benefit	Amount
New style ESA	£138
PIP	£109
Total	£247

Entitlement following changes

Benefit	Amount
State Pension	£50
New Style ESA	£88
Initial entitlement	£138
Reduction due to State Pension	-£50
PIP	£109
Total	£247

John's overall income is unaffected by the change, since the value of his State Pension entitlement is less than the value of ns-ESA, and his partner's income is too high to benefit from the Universal Credit changes.

If John was entitled to a full State Pension of £221, he would have no entitlement to ns-ESA (as this would be entirely eroded by his state pension entitlement), but he would be entitled to receive his State Pension in full. Combined with PIP this would make his income £330.

Current entitlement

Benefit	Amount
New Style ESA	£138
PIP	£109
Total	£247

Entitlement following changes

Benefit	Amount
New Style ESA	£0
Initial entitlement	£138
Reduction due to State Pension	-£138
State Pension	£221
PIP	£109
Total	£330

In this instance, John's income increases by £83 per week, as a result of his entitlement to the State Pension.

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