Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper (June 2025)

Sue Ryder

Sue Ryder is here to make sure everyone approaching the end of their life or living with grief can access the support they need. There is no one size fits all when it comes to how we cope and the help we need, but with our support, no one has to face dying or grief alone. We are there when it matters.

2. What support do you think we could provide for those who will lose their Personal Independence Payment entitlement as a result of a new additional requirement to score at least 4 points on one daily living activity?

3. How could we improve the experience of the health and care system for people who are claiming Personal Independence Payment who would lose entitlement?

We are concerned that reforms within the Universal Credit and Personal Independence Payment Bill may unintentionally make it more difficult for people with a life-limiting condition to receive the Personal Independence Payment (PIP) daily living component.

While people claiming under the special rules for end of life (SREL) will continue to access the enhanced rate of the daily living component, the reforms could adversely impact those with a life-limiting condition who cannot claim via this route. In turn, carers of people with a life-limiting condition also risk losing access to Carer's Allowance or the carer element of Universal Credit, which is contingent on the PIP claimant receiving the daily living component. Combined, the loss of PIP daily living and associated carer benefits could amount to £10,000 a year, a devastating financial blow for households that include someone with a life-limiting condition.

Poverty and financial hardship are a stark reality for many who are nearing the end of life. This can be for a range of reasons; people may have to reduce their working hours or stop work altogether, while also experiencing an increase in costs because of factors such as travelling to more medical appointments, running essential medical equipment and keeping the home warmer.

Sue Ryder polling from 2023 found that finances can determine where people choose to receive care at the end of life, with almost all respondents reporting that the cost-of-living crisis impacted their decision.[1] Factors that led respondents to change their preference for where they would most like to receive end-of-life care included:

- Family working more hours to cover rising costs, so unavailable to provide care (31%)
- Additional pressure to family - increased costs of being cared for at home (29%)

Further, when a person's condition deteriorates and their care needs increase, unpaid carers often struggle with balancing securing the household income and getting their loved one the care they need. 15% of unpaid household end of life carers are in poverty and this proportion doubles in the year following a bereavement.[2]

People with a life-limiting condition should be supported to live well for as long as possible, rather than dealing with the additional uncertainty and financial strain that the reforms to PIP bring. **It is therefore vital to maintain access to the PIP daily living component for all claimants with a life-limiting condition, not just those protected under the SREL.**

9. Should we require most people to participate in a support conversation as a condition of receipt of their full benefit award or of the health element in Universal Credit?

Claimants with a life-limiting illness should be exempt from any conditionality requirements, including the requirement to participate in a support conversation. This is both to reduce unnecessary activity to move people towards work for those who are, sadly, not going to do so, and to remove the risk of a benefit sanction adding further financial pressure to someone who is dying.

This exemption should not only apply to those claiming under the SREL but should be extended to any claimant living with a life-limiting condition. People with a life-limiting condition are dealing with the additional financial, medical, and emotional impacts of their terminal diagnosis, and should not be required to prepare or look for work that it is extremely unlikely they will be able to take up or retain as their condition worsens.

10. How should we determine which individuals or groups of individuals should be exempt from requirements?

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[1] In May 2023 Censuswide polled 201 people aged 18+ who are receiving palliative and end of life care in the UK. Available at: https://media.sueryder.org/documents/Briefing_on_the_impact_of_cost-of-living_on_people_at_the_end_of_life_October_2023.pdf

[2] University of Sheffield (2025), Up to 15 per cent of end of life carers living in poverty, report finds. https://www.sheffield.ac.uk/news/15-cent-end-life-carers-living-poverty-report-finds

Anyone claiming under the SREL or who meets the Severe Conditions Criteria (SCC) should be **exempt** from conditionality requirements, including the requirement to participate in a support conversation.

However, this does not go far enough as there will be many claimants living with a life-limiting condition who do not fall into either of these categories. Around 75% of seriously ill Universal Credit claimants who died in 2024 did not have a claim under the SREL – not everyone who should have this status does.[3] Even with far greater awareness of the SREL, there are people living with a life-limiting condition who cannot claim under this route. For example, those who are likely to live for 18 months or two years, or who have a rare condition that is difficult to prognosticate on.

Some claimants with a life-limiting condition who cannot claim under the SREL will be eligible for the new SCC group, however this will not be the case for everyone. To qualify for the SCC Group, an individual's level of function must always meet Limited Capability for Work and Work-Related Activity (LCWRA).[4] This stringent criteria means that some claimants with a life-limiting condition will be ineligible until their condition deteriorates significantly, despite being unlikely to return to work in the interim and dealing with the fact they are dying.

In order to protect all claimants with a life-limiting condition from the requirement to participate in a support conversation, the Department for Work and Pensions (DWP) must expand eligibility for the SCC group to include people with a life-limiting condition who have Limited Capability for Work (LCW) status.

11. Should we delay access to the health element of Universal Credit within the reformed system until someone is aged 22?

We are concerned about the impact that delaying access to the health element of Universal Credit to age 22 will have on young people with a life-limiting condition. This change is made to enable a Youth Guarantee of employment support, training or an apprenticeship for all 18- to 21-year-olds but this will not help young people with a life-limiting condition, many of whom are unable to work.

Young people with a life-limiting condition often fall through the cracks of social security and health and care support as they transition between children's and adult focused

[3] Written questions and answers - Written questions, answers and statements - UK Parliament (last accessed 27.06.2025)
[4] https://www.gov.uk/government/news/welfare-bill-will-protect-the-most-vulnerable-and-help-households-with-income-boost (last accessed 27.06.2025)

funding streams or services.[5] We are concerned the delaying access to the health element of Universal Credit could further exacerbate the barriers these young people face. This in turn may increase pressures on the carers and families and prevent them from being able to work.

Modern medicine has meant that children with a life-limiting condition are more often living into young adulthood. Between 2001 and 2018, there was a 250% increase in the prevalence of life-limiting and life-threatening conditions in children and young people in England.[6]

The Green Paper says Government will consider special provisions for "where engagement with the guarantee is not a realistic prospect". **It is vital that these include sufficient special provisions for young people under 22 with a life-limiting condition who are too unwell to work.** In a recent speech to IPPR, the Secretary of State for Work and Pensions set out that "Those with the most severe, life-long conditions that will never improve and who can never work will have their Universal Credit protected – including young people aged under 22".[7] It is crucial that this includes young people with a life-limiting condition.

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[5] NCEPOD (2023), The Inbetweeners: A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions moving into adult health services. https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf

[6] Department of Health and Social Care (2024), Independent investigation of the NHS in England. https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england

[7] https://www.gov.uk/government/speeches/welfare-reform-speech-to-the-ippr-by-work-and-pensions-secretary (last accessed 27.06.2025)