

A report by Citizens Advice Gateshead and Society Matters cic



Investigating Special Rules for claimants with terminal illness



June 2025

The Problem

The social security system is failing people at the end of life. Special Rules claims, supported by SR1 forms, are designed to fast-track benefits for those with terminal illnesses. However, systemic failures have led to a breakdown in this critical provision. This situation highlights a deeper issue: a benefits system that is no longer fit for purpose and unable to protect the very people it was designed to support in their most vulnerable moments.

Recommendations for change

Immediate Actions That Directly Impact Clients

1. **Reinstate and Enforce Fast-Track Processing for SR1 Claims** with a strict timeframe. This is a critical first step to ensure timely support for terminally ill clients.
2. **Create a Dedicated SR1 Pathway** for all related benefits (Pension Credit, Carer's Allowance). This will streamline the process for clients and ensure they receive all necessary benefits.
3. **Enhance Communication Channels** with dedicated SR1 helplines and case tracking for clients and advisers, providing timely and compassionate handling. Effective communication is essential for supporting clients through the process.
4. **Introduce Flexibility in Consent and Verification** processes to accommodate terminally ill clients and their carers. This will make the process more humane and less burdensome for those in need.
5. **Implement Proactive DWP Follow-Up** when SR1s are received without a corresponding claim. This ensures no client falls through the cracks.

Systemic Improvements and Training That Support the Overall Process

6. **Improve DWP Administrative Systems** to ensure proper scanning, tracking, and linking of SR1 forms and benefit applications. Efficient administrative systems are crucial for the smooth operation of the process.
7. **Train DWP staff on communication sensitivity**, reducing calls that require claimants, carers, and parents to confirm end-of-life circumstances. Avoid requiring clients to self-disclose terminal status if SR1 is on file. Sensitivity training will improve the experience for clients.
8. **Develop Clearer Guidance and Training** for medical professionals on SR1 eligibility and issuance. Proper guidance ensures that medical professionals can accurately and efficiently issue SR1 forms.
9. **Create a Secure Submission Portal for SR1s** accessible to non-NHS professionals, allowing for secure and direct uploads. This will facilitate the submission process, allowing for a more secure and fast upload.
10. **Cross-Benefit SR1 Integration**, enabling SR1 sharing across PIP, ESA, and UC systems. Integration across systems will streamline the process and ensure consistency in support.

What is an SR1 Form?

An SR1 form is used in the UK to support benefit claims for individuals who are nearing the end of life. This form is part of the "Special Rules" which allow for faster and easier access to certain benefits, higher payments for certain benefits, and the avoidance of medical assessments.

Who is eligible?

If a person is likely to have less than 12 months to live, they can make a fast-tracked claim to the following benefits (for which they are eligible):

- Personal Independence Payment (PIP)
- Universal Credit (UC)
- Employment and Support Allowance (ESA)
- Disability Living Allowance (DLA) for children
- Attendance Allowance (AA)

Who completes the SR1 Form?

A clinician, such as a GP, consultant, hospice doctor, or senior specialist nurse, completes the SR1 form. It provides medical evidence that the patient has a progressive disease and is likely to have less than 12 months to live. This helps expedite the benefits process, ensuring that individuals receive the necessary support promptly.

Timeframes

The Gov website states that:

"The Special Rules allow people nearing the end of life to:

- get faster, easier access to certain benefits"¹

¹ [The 'Special Rules': how the benefit system supports people nearing the end of life - GOV.UK](#)

Attendance Allowance²

The Gov.uk website claims:

“After you send your claim, you’ll be contacted by phone or sent a letter within 3 weeks to explain when you can expect a decision. Once a decision is made, you’ll get a letter explaining the outcome.”

A Citizens Advice Social Welfare Adviser has explained that this was previously an 8-day timeframe.

Information on the Citizens Advice website states that *“once you apply you’ll get a decision back with 2 weeks”*.³

Attendance Allowance: Communication with the DWP

Evidence from a Citizens Advice adviser phone call with the Attendance Allowance helpline reported that:

“Attendance Allowance have just notified me that the guidelines have changed and there is no longer a timeframe in which the claims must be dealt with, and they are no longer considered a priority.” – June 2024

² [Attendance Allowance: Claiming Attendance Allowance if you’re nearing the end of life - GOV.UK](#)

³ [Claiming Attendance Allowance if you're terminally ill - Citizens Advice](#)

Personal Independence Payment (PIP)

No clear timeframe is given on the Gov.uk website.⁴

According to the Citizens Advice website: *"Once the DWP has your SR1 report, they will make a decision on your claim. You'll normally get your first payment within 2 weeks of applying."*⁵

PIP: Communication with the DWP

Evidence from a Citizens Advice adviser phone call with the PIP claims phoneline reported that:

"With PIP, a cover letter and copy of the SR1 was enough to increase an existing claim to allow for quick changes but now they require a new SR1 claim even if a claim is already in payment. They did not volunteer this information however, it took a few delayed claims and clients in hardship – us chasing this up, for them to let us know via telephone."

⁴ [Personal Independence Payment \(PIP\): Claiming PIP if you're nearing the end of life - GOV.UK](#)

⁵ [How to claim PIP if you have a terminal illness - Citizens Advice](#)

Evidence Forms: Key Problems

Part of an adviser's role at Citizens Advice is to submit 'evidence forms' when they see a recurring problem, which can be the result of an unfair policy or practice.

Between January 2024 to January 2025, 294 evidence forms have been raised regarding 'special rules' claims from across the Citizens Advice network.

The following sections summarise the key problems highlighted through these evidence forms, split into different benefits.

Attendance Allowance

1. Delays in Processing Special Rules Claims

Issue:

- The removal of the 8–10 day fast-track processing time for SR1 claims has led to delays of up to 12–13 weeks.

Impact:

- Terminally ill clients have passed away before receiving their entitled benefits, causing financial hardship and emotional distress for families.

2. Administrative Failures by DWP

Issues:

- SR1 forms and AA applications being lost or not scanned properly.
- Claims being processed under normal rules despite SR1 submission.
- Inconsistent communication and lack of updates to clients or their representatives.

Impact:

- Missed payments
- Repeated submissions
- Increased stress for clients and carers.

3. Lack of Fast-Track Pathways for Related Benefits

Issues:

- Pension Credit and Carer's Allowance claims not expedited despite SR1 status.

Impact:

- Clients and carers miss out on vital financial support during critical periods.

4. Poor Communication and Support

Issues:

- DWP helplines disconnecting or providing inconsistent information.
- Clients and carers not being informed of claim status or decisions.

Impact:

- Increased anxiety and confusion
- Administrative burden on already distressed families.

5. Policy and Systemic Gaps

Issues:

- No proactive follow-up from DWP when SR1 is received without a claim.
- Lack of clear guidance on digital signatures and online form glitches.

Impact:

- Inequity in access to support
- Increased workload for caseworkers.

Personal Independence Payment (PIP)

6. Delays in Processing Special Rules Claims

Issue:

- SR1 claims are not being fast-tracked as intended. Many are processed under normal rules, taking weeks or months.

Impact:

- Terminally ill clients often miss out on timely financial support, with some passing away before receiving benefits.

7. Administrative Failures**Issues:**

- SR1 forms lost, misfiled, or not linked to claims.
- Incorrect personal details (e.g., names, addresses) on award letters.
- Claims closed or downgraded without explanation.

Impact:

- Financial loss
- Repeated form submissions
- Increased stress for clients and advisers.

8. Poor Communication and Inconsistent Information**Issues:**

- DWP staff giving conflicting advice about SR1 processes.
- Clients receiving misleading texts or no updates at all.
- Helpline staff unaware of SR1 protocols or unable to access systems.

Impact:

- Confusion and anxiety
- Loss of trust in the system.

9. Inaccessibility and Systemic Barriers**Issues:**

- Long call wait times (up to 45 minutes or more).
- Special Rules helpline often unavailable or disconnected.
- No secure email access for non-NHS professionals to submit SR1s

Impact:

- Delays in claim initiation and processing, especially for vulnerable clients.

10. Failure to Recognise or Act on SR1 Status

Issues:

- Clients with SR1s still required to complete full PIP2 forms or attend assessments.
- SR1s not triggering automatic supersessions or enhanced awards.

Impact:

- Unnecessary administrative burden
- Emotional distress for clients.

11. Lack of Training and Awareness

Issues:

- DWP staff and call handlers unfamiliar with SR1 procedures.
- Medical professionals unaware of when to issue SR1s.

Impact:

- Missed entitlements
- Delays in support.

12. Digital and Access Issues

Issues:

- No online application route for PIP SR1 claims (unlike Attendance Allowance).
- Clients without National Insurance Numbers face unclear processes.

Impact:

- Exclusion of some clients from timely support.

Universal Credit

13. Failure to Automatically Apply LCWRA for SR1 Claimants

Issues:

- Clients with SR1 forms are not automatically awarded the Limited Capability for Work and Work-Related Activity (LCWRA) element.

Impact:

- Financial loss (up to £390/month)
- Delays of several months
- Clients are wrongly placed in work-related activity groups or asked to attend assessments.

14. Lack of Integration Between DWP Departments

Issues:

- SR1 forms submitted for PIP or ESA are not shared with UC teams.

Impact:

- Clients must resubmit SR1s
- Repeated form-filling and communication
- Missed entitlements
- Duplicated effort.

15. Inappropriate Demands on Terminally Ill Clients

Issues:

- Requests to complete UC50 forms despite SR1.
- Demands to attend Jobcentre appointments or work-focused interviews.
- Clients being asked to confirm their terminal status via journal messages.

Impact:

- Emotional distress
- Breach of dignity and privacy

- Potential breaches of the Public Sector Equality Duty.

16. Poor Communication and Administrative Errors

Issues:

- SR1s lost or not actioned.
- Incorrect benefit calculations.
- Clients placed in incorrect UC groups.

Impact:

- Delayed or incorrect payments, increased stress and confusion, additional burden on advisers and healthcare professionals.

17. Barriers to Accessing UC for Vulnerable Clients

Issues:

- No online SR1 submission route for advisers.
- Clients without digital access or English fluency struggle to apply.

Impact:

- Missed entitlements
- Increased reliance on family or advisers
- Financial hardship.

18. Inadequate Staff Training and Awareness

Issues:

- UC staff unaware of SR1 implications or LCWRA rules.
- Incorrect advice given to clients and advisers.

Impact:

- Misapplication of rules
- Delays in benefit awards
- Erosion of trust in the system.

19. Failure to Respect Claimant Autonomy and Privacy

Issues:

- Clients unaware of their prognosis being forced to self-report terminal illness.
- SR1 status not being used to shield clients from unnecessary contact.

Impact:

- Psychological harm
- Breach of medical confidentiality
- Undermining of patient-centred care.

Employment Support Allowance (ESA)

20. Delays in Processing Special Rules Claims

Issues:

- ESA claims under SR1 are not being fast-tracked as they should be.

Impact:

- Clients wait weeks or months for payments
- Loss of National Insurance credits
- Financial stress during critical health periods.

21. Inadequate Phone Support and Communication

Issues:

- Long hold times (up to 2 hours).
- Calls dropped or disconnected.
- ESA enquiry line misrouting calls to new claims team.

Impact:

- Wasted time and effort for clients and caseworkers
- Delays in resolving urgent issues
- Increased frustration and anxiety.

22. Failure to Recognise SR1 Status

Issues:

- Clients with SR1 still being asked to complete ESA50 forms.
- SR1 not triggering automatic support group placement.

Impact:

- Unnecessary form-filling and assessments
- Delayed access to entitled benefits
- Emotional toll on clients already coping with terminal illness.

Disability Living Allowance (DLA)

23. Inappropriate and Distressing Communication from DLA

Issues:

- DLA is calling parents to confirm that their child is likely to die within 12 months, even after receiving an SR1 from a healthcare professional.

Impact:

- Emotional trauma for parents
- Risk of claims being downgraded or delayed if parents cannot confirm prognosis
- Potential for families to miss out on fast-tracked support.

Future concerns

Citizens Advice advisers have observed that delays and changes in the processing of benefits under the Special Rules have been most prominent in Attendance Allowance claims. Alarming, these issues have now extended to Personal Independence Payment applications. Looking ahead, there is growing concern that Disability Living Allowance, primarily supporting children under 16, may be the next to be affected. The current trend, where claims are no longer being fast-tracked despite the submission of SR1 forms, suggests that children and their families who urgently need this vital support could soon face similar delays.