

Special Rules for Terminal Illness (SRTI)

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Introduction

1. This chapter explains how to make decisions regarding individuals who are terminally ill. The rules set out below are known as special rules for terminal illness (SRTI).
2. This chapter relates to individuals in receipt of Scottish Adult Disability Living Allowance (Scottish Adult DLA).
3. The SRTI rules apply to individuals who meet the legal definition of terminal illness in the Social Security (Scotland) Act 2018.
4. A person is considered to be terminally ill if "the individual has a progressive disease that can reasonably be expected to cause the individual's death"¹.

1 SS (S) Act 2018, Schedule 5, para 1(2)

5. Individuals are diagnosed by a registered medical practitioner (RMP) or a registered nurse (RN)¹. A RMP is a doctor who has current registration and a licence to practise with the General Medical Council. A RN is a nurse who has current registration and a licence to practise with the Nursing and Midwifery Council. The decision of whether the individual meets the terminal illness definition can only be determined by a RMP or a RN.

The RMP or RN must be involved in the diagnosis and/or care of the individual and must be acting in their professional capacity.

Where the person who is terminally ill resides in the EEA, Switzerland or Gibraltar, the RMP or RN has to be registered with a licence to practise with the professional body equivalent to the General Medical Council or the Nursing and Midwifery Council in that country.

1 Scottish Adult DLA Regs, Reg 20(11)(a)(b)

6. If an individual has a progressive disease but is not terminally ill, the special rules for terminal illness do not apply.
7. The RMP or RN is legally required to follow the Chief Medical Officer (CMO) guidance¹ which supports RMPs and RNs in reaching their clinical judgement of terminal illness.

*1 SS (S) Act 2018, Schedule 5, para 1(2)(3)
1 Scottish Adult DLA regs, reg 20 (9)*

8. Where the person who is terminally ill resides in the EEA, Switzerland or Gibraltar, the registered RMP or RN with a licence to practise need not have regard to such guidance if it would not be reasonable to insist that they do so in making their clinical judgement.²

2 Scottish Adult DLA regs, reg. 20(10)

9. A Benefits Assessment under Special Rules in Scotland (BASRiS) form should be completed for a terminally ill adult who is entitled to Scottish Adult DLA under the Special Rules for Terminal Illness in Scotland. Social Security Scotland will also accept an SR1 form or DS1500 form.

10. A BASRiS form can only be completed by a registered medical practitioner (RMP) or registered nurse (RN) with a licence to practise.

11. The BASRiS form replaces the SR1/DS1500 for Scotland's new forms of Disability Assistance.

12. Individuals who are eligible under the Special Rules will have a different case transfer journey to those who are eligible under the main benefit rules for Scottish Adult DLA. Please see the Case Transfer chapter for more information.

Need for Discretion – harmful information

13. A medical professional may decide not to tell the individual that they are terminally ill or other information relating to their condition. They will only withhold this information if they have decided that telling the individual would be likely to cause serious harm to their physical or mental health. ¹ This is referred to as harmful information. In these situations Social Security Scotland must not disclose this information to the individual. If the RMP or RN has specifically identified the information as needing to be withheld from a family member then Social Security Scotland must not disclose this to that family member.

1 SS(S)A 2018, s. 62A(2) and (3)

14. It will be rare that a medical professional withholds harmful information from an individual so this will likely affect only a small number of individuals who are terminally ill.

15. Case managers must not in any circumstances mention to the individual or anyone else that the individual:

- is terminally ill
- has a diagnosis of a terminal illness.

16. This is because:

- the individual or appointee might not know the individual is terminally ill
- knowing about a terminal illness diagnosis could cause the individual serious harm or distress.

An exception to this is that case managers can refer to the diagnosis with a third party who is reporting a terminal illness diagnosis on behalf of the individual.

17. However, if an individual refers to themselves as being terminally ill and you know that information has not been withheld you can acknowledge this.

18. Where harmful information is withheld, refer the client with any questions about their diagnosis to the RMP or RN who provided the clinical judgement. Tell the RMP or RN that the client has raised the issue so they can prepare for their patient contacting them.

19. During a social security appeal, the First-tier Tribunal or the Upper Tribunal may give a direction prohibiting the disclosure of a document or information to a person ("the recipient") if:

- the document or information relates to the physical or mental health of a person,
- a RMP or RN has advised either the Tribunal, or one or more of the parties, that disclosure of the information is likely to cause serious harm to the recipient's, or some other person's, physical or mental health,
- the Tribunal is satisfied that disclosure of the harmful document or information would be likely to cause serious harm to the physical or mental health of the recipient or some other person,
- the Tribunal is satisfied that it is in the interests of justice and proportionate to give such a direction.¹

¹ *The First-tier Tribunal for Scotland Social Security Chamber (Procedure) Regulations 2018, Schedule, para 14(2)-(6); The Upper Tribunal for Scotland (Social Security Rules of Procedure) Regulations 2018, Schedule, para 17(2)-(6)*

20. See the chapters on Appeals to the First-tier tribunal and Appeals to the Upper Tribunal for more information about how the Tribunal can issue such a direction.

Example: harmful information has been withheld

Agatha's award has transferred from DLA to Scottish Adult DLA. Her daughter Fiona tells Social Security Scotland that Agatha is now terminally ill but she does not know this. Her clinician has withheld the information from Agatha because they believe it would be harmful for her to know this.

A Social Security Scotland practitioner contacts the RMP/RN named by Fiona to ask them whether Agatha meets the terminal illness definition and whether a BASRiS form is appropriate.

The practitioner also establishes whether the RMP/RN has withheld information from Agatha because they have determined it would be likely to cause serious harm to her mental or physical health.

The RMP/RN sends a BASRiS form which confirms that Agatha does not know she is terminally ill because the RMP/RN has withheld this information from her. When communicating with Agatha, Social Security Scotland makes no reference to terminal illness, special rules or to the BASRiS form so as not to reveal to Agatha that her condition is terminal.

Example: Query from an individual where an award has changed but harmful information has been withheld

An individual, aged 55, contacts Social Security Scotland to ask why their payments have increased. They were previously receiving the care component of Scottish Adult DLA award at the lowest rate and the lower rate of the mobility component.

A RMP/RN has sent Social Security Scotland a BASRiS form confirming that the individual is terminally ill, but they are unaware of this. The RMP/RN tells Social Security Scotland that it would be harmful to the individual to know they are terminally ill.

The Case Manager completed a determination without application and determined that the individual meets the criteria to receive the highest rate of the Scottish Adult DLA care component under special rules.

A new award was issued to the individual by Social Security Scotland, confirming the change of entitlement. The award notification makes no reference to special rules.

The Case Manager speaks to the individual and advises that a change in condition has led to a change in payment. The Case Manager can refer the individual to speak with the RMP or RN who provided further information about their condition. The Case Manager makes no reference to terminal illness, special rules or the BASRiS form. They can then contact the RMP or RN to let them know their patient may be in touch for more information about their condition.

Special Rules for Terminal Illness

Special Rules Requirements

21. The person who is terminally ill does **not** need to:

- have a consultation with Social Security Scotland¹
- have been living in the UK for a set period of time²

- have the medical condition for a minimum period of time before eligibility can begin³

The backwards test does not apply to individuals who are terminally ill⁴.

*1 SS (S) A 2018, Schedule 5 para 10
2 Scottish Adult DLA regs, reg. 10(6)(a)*

*3 SS (S) A 2018, Schedule 5, para. 9 and Scottish Adult DLA regs, reg. 20(3)
4 Scottish Adult DLA regs, reg. 20(1) and 20(2)*

Rates of Payment

22. Special rules for terminal illness awards are ongoing without review. There will be no review period and an individual remains eligible unless they have informed Social Security Scotland that their circumstances have changed.

23. The rate of Scottish Adult DLA that an individual is entitled to is dependent on whether they meet the criteria set out in the Scottish Adult DLA regulations.

24. Scottish Adult DLA has two components: the care component and the mobility component. The care component has three rates: lowest, middle and highest. The mobility component has two rates: lower and higher. ¹

1 Scottish Adult DLA Regs, Reg 29(1)(2)

25. Individuals who are terminally ill and are entitled to Scottish Adult DLA automatically get the highest rate of entitlement for the care component. ¹

1 Scottish Adult DLA regs, reg. 20(1)

26. Individuals who become terminally ill before reaching the 'relevant age' and are entitled to Scottish Adult DLA automatically get the higher rate of entitlement for the mobility component. ²

2 Scottish Adult DLA regs, reg. 20(2)(a)

27. 'Relevant age' means state pension age, or 65, whichever is higher¹.

1 Scottish Adult DLA regs, reg.2

28. Individuals who become terminally ill after reaching the relevant age whilst entitled to Scottish Adult DLA continue to receive the mobility component at the rate they received prior to reaching the relevant age. ¹

1 Scottish Adult DLA regs, reg. 20(2)(b)

Notification of changes in circumstances

29. The individual must tell Social Security Scotland of any change in circumstances that can affect the level of assistance that an individual is paid. This can include but is not limited to changes in:

- diagnosis (including if the individual is no longer considered to be terminally ill)
- other entitlement criteria such as residence

Supporting information for SRTI

30. The supporting information to confirm a terminal illness diagnosis is either a BASRiS form, an SR1 form or a DS1500 form. The BASRiS form can only be completed by a registered medical practitioner (RMP) or registered nurse (RN) with a licence to practise.
31. Social Security Scotland will accept the SR1 form or DS1500 form used by the Department for Work and Pensions (DWP) to confirm a terminal illness diagnosis. All references to the BASRiS form or the clinical judgement in this guidance also refer to the SR1 form and DS1500 form.
32. The supporting information confirming a terminal illness diagnosis may alternatively be provided over the phone (the clinical judgement or 'verbal' BASRiS) or in a clinician's letter. The registered medical practitioner (RMP) or registered nurse (RN) should subsequently submit a BASRiS form to Social Security Scotland within 28 days.
33. A Social Security Scotland practitioner may be required to contact the RMP or RN to request or clarify the clinical judgement verbally. On receipt of this verbal confirmation a case manager can progress to payment.
34. Where a verbal BASRiS has been received, the case manager does not need to wait for the electronic (pdf), webform (digital portal) or paper BASRiS form to arrive in order to process the payment.
35. Only a registered medical practitioner (RMP) with a licence to practise or registered nurse (RN) with a licence to practise can complete a BASRiS form. The RMP or RN must meet both these criteria¹:
 - be involved with the diagnosis or care of the person who is terminally ill
 - be acting in their professional capacity.

1 Scottish Adult DLA regs, reg. 20(11)(a)
36. If an individual does not live in Scotland but meets the eligibility criteria¹ then an appropriate registered healthcare professional with a licence to practise in the country they reside in can provide a clinical judgement of terminal illness and complete a BASRiS.

1 Scottish Adult DLA regs, reg 20(11)(b)
37. The healthcare professional must be equivalently qualified to a RMP or a RN in an EEA state, Gibraltar or Switzerland.
38. This healthcare professional must have a licence to practise and be registered with a professional body equivalent to the General Medical Council or Nursing

and Midwifery Council in their country. They must be involved in the care or diagnosis of the patient and must be working in their professional capacity¹.

1 Scottish Adult DLA regs, reg 20(11)(b)

39. Normally a healthcare professional in an EEA state, Gibraltar or Switzerland would take account of the CMO guidance. However if the particular circumstances mean it would not be reasonable in the circumstances to insist that they use the CMO guidance then Social Security Scotland can still accept their clinical judgement¹.

1 Scottish Adult DLA regs, reg. 20(10)

Date of Award

40. An individual who is terminally ill becomes entitled to assistance from whichever of these dates is earliest¹:

- the date a RMP or RN makes a clinical judgement that the individual meets the terminal illness definition
- the date Social Security Scotland becomes aware that a current client is terminally ill either by them notifying through a change of circumstances or otherwise (the “applicable date”). The clinical judgement is the date captured on the BASRiS form. If the clinical judgement is taken verbally and a BASRiS form is later sent to Social Security Scotland then the relevant date is that of the verbal clinical judgement.

1 Scottish Adult DLA regs, reg. 20(5)

41. Where the date of the clinical judgement is earlier than the date the change of circumstances notification is received, but also within 26 weeks of this, or the date the Scottish Ministers become aware that a Scottish Adult DLA recipient is terminally ill,² the award will commence from the date of the clinical judgement.

2 Scottish Adult DLA regs, reg. 20(6)

42. The date of award can be no earlier than 21 March 2025, which is the date the Scottish Adult DLA Regulations commenced.

Example: clinical judgement is dated earlier than the date the client informed Social Security Scotland about their terminal illness

On 30 August, Dylan informed Social Security Scotland that he had been diagnosed with a terminal illness. A BASRiS form then arrived with a clinical judgement date of 29 March, a date 22 weeks earlier than Dylan’s reported change of circumstances date. The date the award starts is 29 March because the clinical judgement date is within 26 weeks of the change of circumstances date.¹

1 Scottish Adult DLA regs, reg. 20(6)

43. Many BASRiS forms will be submitted directly to Social Security Scotland by the RMP or RN. However, there may be situations when an individual or their third party has been given the BASRiS form by their clinician and then either fails to submit the BASRiS or delays in submitting it to Social Security Scotland. Or an individual may have received a diagnosis of terminal illness from their RMP/RN but not a BASRiS form.

44. If the clinical judgement date is more than 26 weeks earlier than either the date a change of circumstances is reported or the date that Social Security Scotland become aware that a Scottish Adult DLA client is terminally ill, then a practitioner must contact the individual's RMP or RN.

45. The RMP or RN who provided a clinical judgement and/or completed the BASRiS form must confirm the individual's terminal illness diagnosis is still accurate. This confirmation can be verbal. ¹

1 Scottish Adult DLA regs, reg. 20(7)

46. If the terminal illness diagnosis is confirmed by the RMP/RN, the date the award will commence is backdated to a maximum of 26 weeks before the date a change of circumstances was reported (or 26 weeks before the date the Scottish Ministers become aware that a Scottish Adult DLA recipient is terminally ill.) as long as Scottish Adult DLA Regulations have commenced. ¹

1 Scottish Adult DLA regs, reg. 20(7)

Example: confirming a BASRiS is still accurate

Eve's RMP gives her a completed BASRiS form dated 7 May. Eve is too distressed at the time to notify Social Security Scotland of her terminal diagnosis.

On 20 December Eve contacts Social Security Scotland to tell them about her terminal illness and then submits the BASRiS form dated 7 May. A practitioner in Social Security Scotland contacts Eve's RMP/RN to confirm the terminal diagnosis is still accurate since the BASRiS is dated more than 26 weeks earlier than change of circumstances date.

The RMP/RN confirms the terminal diagnosis is still accurate. The award can be calculated from 26 weeks prior to 20 December because Scottish Adult DLA Regulations had commenced. An appropriate back payment is made.

Example: backdated payments required where uprating has also occurred

Social Security Scotland receives notification from a client about their terminal illness diagnosis on 23 September. The client submits a BASRiS form that is dated (clinical judgement) 30 weeks earlier.

After confirming the individual's terminal illness diagnosis is still accurate with the RMP/RN, Social Security Scotland will make payments from 26 weeks before the date the client reported their change of circumstances.

The higher rates for Scottish Adult DLA were uprated on the first Monday after 6 April. Payments for the weeks prior to the uprating date will be calculated using the rates prior to the uprating. Payment for the weeks after the uprating date will be calculated at the uprated rates.

47. If an SR1 form or DS1500 form is received as an alternative to the BASRiS or clinical judgement, the date of diagnosis on the form is regarded as the date of the clinical judgement and therefore confirmation of the date that the person meets the Scottish terminal illness definition.
48. Entitlement to disability assistance cannot precede the date the relevant legislation came into effect. Social Security Scotland can accept an SR1, DS1500 or BASRiS with a clinical judgement date that precedes the date Scottish Adult DLA launched. However, the award cannot commence until the date the Scottish Adult DLA regulations came into force.

Change of Circumstances

49. The individual must notify Social Security Scotland of any change in circumstances that could possibly result in a change in the level of the individual's entitlement or appropriate value of payment. This includes but is not limited to:
- if the individual is living in alternative accommodation
 - a change of health condition or care needs
 - a change in diagnosis meaning the individual is no longer considered to be terminally ill
50. If an individual is terminally ill, changes to the appropriate value of payment where the individual is in alternative accommodation follow the standard Scottish Adult DLA rules for alternative accommodation.
51. Payment continues after 28 days when the individual is in a hospice, is terminally ill and Social Security Scotland have been informed that the individual is terminally ill¹.

1 Scottish Adult DLA regs, reg. 24(1)

52. A hospice is a palliative care institution that isn't publicly funded and whose main function is to provide palliative care for people suffering from a progressive disease in the final stages¹

1 Scottish Adult DLA regs, reg. 24(2)

53. A hospice is a separate organisation to a hospital.

54. If, however, an individual is receiving palliative care within a specialised ward or facility in a hospital or care home, the individual is considered to be in a publicly funded hospital or care home. Their award will be £0 rated on the 29th day.

Changes when an individual already entitled to Scottish Adult DLA becomes terminally ill

55. If an individual already in receipt of Scottish Adult DLA becomes terminally ill, a case manager should make a determination without application setting out the individual's new level of entitlement.

56. This could happen in two ways:

- the individual informs Social Security Scotland that they have become terminally ill.
- a clinical judgement is received by Social Security Scotland for an individual currently in receipt of Scottish Adult DLA.

57. On receipt of a clinical judgement, the individual's award becomes subject to the special rules for terminal illness. Social Security Scotland will make a determination without application so that the individual receives the appropriate award. There is no review date.

58. The new level of entitlement begins no earlier than 21 March 2025 which is the date the Scottish Adult DLA Regulations commenced and from the earlier of:

- the date that the RMP/RN made the clinical judgement that the individual met the terminal illness definition. The clinical judgement may be provided on the phone, via a letter or on the BASRiS (or equivalent) form.
- the date Social Security Scotland were notified by the individual or otherwise about their terminal illness¹.
Where the BASRiS (or equivalent) date is earlier than the individual's reported terminal illness and within 26 weeks of the reported date, the award will commence from the clinical judgement date on the BASRiS. If the clinical judgement date is more than 26 weeks earlier than the reported terminal illness, the RMP/RN must confirm that the individual's terminal illness diagnosis is still accurate. If this confirmation is received, the date the award will commence is still only backdated to a maximum of 26 weeks.

1 Scottish Adult DLA regs, reg. 20(7)

Changes in award due to new information received

59. Social Security Scotland can make a determination without application if it becomes aware of a change of circumstances which would possibly result in an alteration to the components/rates of Scottish Adult DLA payable, or cause entitlement to Scottish Adult DLA to end.

60. This can affect one or more of the following:

- whether payment of assistance can continue
- the rate/components of assistance which the individual receives.

Case managers might need to ask for further information to make the decision.

61. Examples of relevant changes in circumstances include:

- a change in prognosis
- admission to publicly funded residential care or to legal detention
- change to immigration status
- official error
- moving from Scotland to another part of the UK.

For example, a terminally ill individual admitted to a publicly funded care home or hospital (not a hospice) would:

- if entitled, still be paid Scottish Adult DLA for the first 28 days only.
- stop being paid both components of Scottish Adult DLA on the 29th day of their stay in a publicly funded care home or hospital (not including a hospice).

62. A terminally ill individual admitted to a hospice, as defined above, will continue to receive Scottish Adult DLA payments after 28 days.

63. A terminally ill individual paying for their own care will continue to receive Scottish Adult DLA payments after 28 days.

64. Where an individual reports that they are no longer terminally ill due to a change in prognosis, a case manager makes a determination without application, setting out the individual's new rate of entitlement by applying the normal rules.

Re-determinations and Appeals

65. Re-determinations involve Social Security Scotland reconsidering an existing determination of entitlement to assistance.

66. An individual can request a re-determination of any determination of entitlement¹.

1 SS(S)A 2018, s. 41(1)

67. Individuals can request a re-determination by either calling Social Security Scotland, or completing the re-determination form that accompanies every determination of entitlement.

68. The individual has 42 calendar days from the date on which they were informed of a determination. The date the individual is informed is the date of issue of the determination plus 48 hours¹.

1 Scottish Adult DLA Regs, reg. 49(1) and Social Security Scotland Act s. 62(1)(2)

Re-determination of a successful SRTI award

69. An individual or their representative may ask for a re-determination of the start date of payment for a successful SRTI award.

Example: re-determination of award date

An individual in receipt of Scottish Adult DLA informed Social Security Scotland that they had become newly terminally ill on 10 March. Following this a BASRiS form for the individual is received which has a date of clinical judgement of 1 March.

The award was incorrectly processed to have a start date of 10 March.

The individual requests a re-determination because the start date of their award of Scottish Adult DLA should match the date on the BASRiS form.

The Client Experience Officer carries out a re-determination and decides that the new award start date is 1 March. The individual should be paid any arrears of Scottish Adult DLA between 1 and 10 March.

Re-determination of an unsuccessful SRTI award

70. An individual or their representative can ask for a re-determination of an unsuccessful SRTI award. An individual's SRTI award can be unsuccessful because of one, several or all the following reasons:

- confirmation of terminal illness not received
- they do not meet residence criteria
- they do not have recourse to public funds
- case manager has wrongly concluded that the diagnosis was not given by a RMP or a RN who is involved in the diagnosis or care of the individual.

71. If the individual does not meet the conditions for assistance, they would need to:

- ask for a re-determination and
- give supporting information which confirms that they do meet the conditions for the assistance, for example a BASRiS form.

[End of chapter]