

Special Rules for Terminal Illness (SRTI)

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Introduction

1. This chapter explains how to make decisions regarding applications for individuals who are terminally ill. The rules set out below are known as special rules for terminal illness (SRTI) applications.
2. This chapter relates to individuals applying for Adult Disability Payment (ADP).
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 with the General Medical Council. A RN is a nurse who has current registration 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 a member of the professional body equivalent to the General Medical Council or the Nursing and Midwifery Council in that country.

1 ADP regs, reg. 26(10)(a)(b)

6. If an individual has a progressive disease but is not terminally ill, the special rules for terminal illness do not apply. This means they need to apply through the usual application process.
7. The RMP or RN must follow the Chief Medical Officer (CMO) guidance¹ which supports RMP's and RN's in reaching their clinical judgement of terminal illness.

1 SS (S) Act 2018, Schedule 5, para 1(2)(3)

Where the person who is terminally ill resides in the EEA, Switzerland or Gibraltar, the RMP or RN 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 ADP regs, reg. 26(9)

8. A Benefits Assessment for Special Rules in Scotland (BASRiS) form should be completed for a terminally ill adult applying for Adult Disability Payment in Scotland.
9. The BASRiS form will replace the DS1500 for Scotland's new forms of Disability Assistance.

Need for Discretion

10. 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. 62(A)(3)

11. 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.
12. Case managers must not in any circumstances mention to the individual or anyone else that the individual:
 - is terminally ill
 - has a diagnosis of terminal illness.

13. An exception to this is that case managers can refer to the diagnosis with a third party who is making the SRTI part of the application on behalf of the individual. An example where this could be necessary is if the third party is completing the application with a case manager over the phone.

14. 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.

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

16. Where harmful information is withheld, refer any questions about diagnosis to the RMP or RN who provided the clinical judgement.

17. 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 registered medical practitioner or a registered nurse has advised either the Tribunal, or one of 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 direction¹

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

An individual contacts Social Security Scotland to enquire why their payments have changed. They were previously receiving an ADP award for the daily living component at the standard rate and the mobility component at the enhanced rate.

A Registered Medical Practitioner (RMP) or Registered Nurse (RN) sent in a BASRiS form which confirmed that the individual is terminally ill, but that they are unaware of this. The RMP or 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 they met the criteria to receive the ADP award under special rules. This means the award will increase to the enhanced rate for both the mobility and daily living components.

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 BASRiS form.

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)

Special Rules for Terminal Illness

Special Rules Requirements

19. 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
[Link to TBD residence and presence chapter]
- have the medical condition for a specific period of time before they apply³
- have the medical condition for a minimum period of time before eligibility can begin⁴

The backwards and forward tests do not apply to individuals who are terminally ill.

*1 SS (S) A 2018, Schedule 5, Chapter 3 paragraph 10
2 ADP regs, reg. 15 (6)*

3 SS (S) A 2018, Schedule 5, para. 9 and ADP regs, reg. 26(2)

4 SS (S) A 2018, Schedule 5, para. 9 and ADP regs, reg. 26(2)

Components and Rates

20. 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.

21. ADP has two components:

- the daily living component
- the mobility component.

The daily living component has 2 rates (standard & enhanced) and the mobility component has two rates (standard & enhanced).

22. Individuals who are terminally ill before reaching state pension age, who qualify for ADP, automatically get the enhanced rate of the daily living and mobility components¹.

1 ADP regs, reg. 26(1)

Notification of changes in circumstances

23. 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 changes in:

- diagnosis (including if the individual is no longer considered to be terminally ill)
- other entitlement criteria such as residence¹

1 ADP regs, reg. 15

Eligibility

24. The individual for whom an application for assistance is being made must meet the standard eligibility requirements for all individuals:

- meet the age criteria
- meet certain residence and presence criteria
The past presence test in the common travel area condition does not apply to people who are terminally ill.¹

1 ADP regs, reg. 15(6)

- have a right to public funds. For example someone seeking asylum to the UK who has not yet been granted asylum does not have a right to public funds.

To be eligible under special rules terminal illness the person for whom an application for assistance is being made must also:

- be diagnosed as terminally ill

25.

26. Social Security Scotland directs individuals resident in other parts of Great Britain to the Department for Work and Pensions and individuals resident in

Northern Ireland to the Department of Communities. Where a client is moving between Scotland and the rest of the UK refer to the chapter below.

27. SRTI applications for ADP can be made by either:

- The individual
- any third party including friend, family member or representative from an organisation as long as they have the individuals consent to complete the application on their behalf.

Example: application from a family member

John, aged 46 is terminally ill. His doctor has completed a BASRiS form and explained his terminal diagnosis to him. John's sister completes an application on his behalf. All communication is with John as the application is in his name.

28. The age criteria for ADP applies equally if an applicant is terminally ill or current Adult Disability Payment client becomes terminally ill. This means the rules limiting eligibility to the mobility component apply if the individual is over state pension age at the point they become terminally ill. This includes if an application for Adult Disability Payment is received for an individual who is over state pension age but was in receipt of Adult Disability Payment within a year of making the new application. See the relevant chapter to follow these rules.

29. Where the clinical judgement was made (likely to be the date the BASRiS is signed) before the date the individual reached state pension age the rules limiting any increase to the mobility component do not apply. This includes scenarios where both:

- the SRTI ADP application is received after the individual reaches state pension age
- the clinical judgement is made before the individual reaches state pension age but is received by Social Security Scotland after the individual reaches state pension age

This is because their entitlement would be determined to start on the date of their clinical judgement, and so they will have been found to be entitled to an award before they reached state pension age.¹

1 ADP regs, reg. 25(5)

Supporting information for SRTI

30. The supporting information to confirm a terminal illness diagnosis is either a BASRiS form or a DS1500 form.

31. Social Security Scotland will accept the DS1500 form used by the Department for Work and Pensions (DWP) to confirm a terminal illness diagnosis. All references to the BASRiS form in this guidance also refer to the DS1500 form.

32. Only a RMP or RN 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 ADP regs, reg. 26(10)(a)(i) and (ii)

33. If an individual does not live in Scotland but meets the eligibility criteria¹ then an appropriate healthcare professional in the country they reside in can make the diagnosis and complete a BASRiS form.

1 ADP regs, reg 20 and reg. 26(10)

34. The healthcare professional must be equivalently qualified to a RMP or a RN in an EEA state, Gibraltar or Switzerland.

35. This healthcare professional must be a member of 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 ADP regs, reg 26(10)(b)

36. 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 ADP regs, reg. 26(9)

37. Social Security Scotland can take verbal confirmation of a terminal illness diagnosis from an RMP or RN if there is no BASRiS or DS1500 form with the application.

38. A Social Security Scotland practitioner will contact the RMP or RN to request the BASRiS information. On receipt of this verbal confirmation a case manager can process to payment.

39. The case manager does not need to wait for the electronic or paper BASRiS form to arrive.

Example: an SRTI application for ADP without an accompanying BASRiS form

An individual submits an application for ADP under special rules because they have a progressive disease. There is no accompanying BASRiS form.

A Social Security Scotland practitioner contacts the healthcare professional identified on the individual's application form to enquire if they meet the terminal illness definition. The practitioner must ensure they are contacting a RMP or a RN.

If the RMP or RN determines that the individual does meet the terminal illness definition they can confirm this on the telephone. The RMP or RN would then complete the BASRiS form and send this to Social Security Scotland within one month. Following verbal confirmation, the case manager can process the application.

If the RMP or RN determines that the individual does not meet the terminal illness definition the individual will be told that they have not met the criteria for an award under SRTI. They will be asked if they wish to be considered for an ADP award under normal rules. If so further information will be requested from the individual.

40. Social Security Scotland can accept information supporting an application from a third party which prompts exploration of whether an application through the usual route might be from an individual who is terminally ill. This includes when the individual has not applied for assistance under SRTI.

This can be part of the initial application or information provided following receipt of an application.

Applications from a third party

41. Applications under SRTI rules can be submitted by a third party. There are no restrictions on who can submit a third party SRTI application.

42. Third party individuals may include:

- friends
- relatives
- a representative from an organisation, for example:
 - advice or welfare rights organisations
 - professionals such as social workers
 - nurses or doctors.

43. The third party must tell the individual they are applying for assistance for them and must gain the individual's consent to do so. The third party will have to confirm as part of the application that they have gained the individual's consent.

44. The individual does not have to sign the application form for assistance under SRTI. .

45. The individual who is terminally ill is still treated as the individual who applies for the assistance, even if a third party makes the application for them.

46. A third party can make an initial application. However, all further communication must be with the person who is terminally ill.

47. There are a number of ways all individuals can receive the support of a third party representative in their interactions with Social Security Scotland.

48. This is not a legal representative but a person the individual has nominated to support them.

49. This is different to a third party making an application on behalf of someone who is terminally ill. A third party making an application will not have any involvement with Social Security Scotland after submitting the application.

50. A third party representative could continue to support the individual in their interactions with Social Security Scotland.

51. Third party representatives are available to all individuals but are likely to be of particular benefit to SRTI individuals.

Example: third party application

James is terminally ill. A Macmillan nurse involved in his care asks him if he would like her to submit an application on his behalf for ADP.

James agrees and the nurse submits the application.

In completing the application the nurse needs to confirm that she has James' consent. All future communication is between Social Security Scotland and James.

Date of Award

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

- the date Social Security Scotland receives their application (which included information about the individual's terminal illness)
 - the date a RMP or RN makes a clinical judgment that the individual meets the terminal illness definition
- Where this clinical judgement is received on a BASRiS form it is the date the BASRiS form is signed (up to a maximum of 26 weeks prior to application being received).

1 ADP regs, reg. 26(4)

53. Where the date on the BASRiS form is earlier than the date the application is received but also within 26 weeks of the date the application is received, the award will commence from the date on the BASRiS form.²

2 ADP regs, reg. 26(5)

This date can be no earlier 21 March 2022 which is the the date the ADP Regulations commence.

Example: BASRiS form is dated earlier than date application is received

Catherine's BASRiS form arrives. It was signed and dated 30 August. An application form then arrives on 12 September. The date the award starts is taken from 30 August, because the BASRiS form was signed before the date the application is received.

54. Most BASRiS forms will be submitted directly to Social Security Scotland by the RMP or RN. However there may be situations when an individual has been given the BASRiS form but the individual either fails to supply or delays in supplying the form to Social Security Scotland.

55. If the BASRiS date is more than 26 weeks earlier than the date the application is received, then a practitioner must contact the RMP or RN.

56. The RMP or RN who completed the BASRiS form must confirm the individual's terminal illness diagnosis.

57. If the terminal illness diagnosis is confirmed the date the award will commence is backdated to a maximum of 26 weeks before the date of application¹.

¹ ADP regs, reg. 26(6)

Example: backdated payments required to meet correct start date

Jane's RMP completes a BASRiS form dated 7 May for Jane and gives it to her mother. Jane's mother is too distressed at the time to apply for assistance.

On 20 December she decides to apply and also submits the BASRiS form. A practitioner in Social Security Scotland contacts the RMP to confirm the terminal diagnosis.

Once this is confirmed the award is calculated from 26 weeks prior to 20 December and an appropriate back payment is made.

Example: backdated payments required where uprating has also occurred

Social Security Scotland receives an application on 23 September accompanied by a BASRiS form that was signed on 26 March. The date the BASRiS form was signed is 30 weeks before the date the application is received. After confirming the individual's terminal illness diagnosis with the RMP or RN, Social Security Scotland will make payments from 26 weeks before the date the application was received.

The enhanced rate for the daily living component was uprated on 1 April. Payments for the 1 week prior to 1 April will be calculated on the rate prior to the uprating. Payment for the 25 weeks after 1 April will be calculated at the uprated rate.

58. Entitlement to disability benefit cannot precede the date the relevant legislation came into effect. The Adult Disability Payment regulations come into force on the 21 March 2022. Social Security Scotland can only accept a BASRiS for ADP

if the date on the BASRiS is on or after the date Social Security Scotland begins delivering ADP.

Application not made under SRTI

59. Social Security Scotland has a duty to identify potential SRTI individuals at any stage of the application process. SRTI individuals can be identified in the triage of applications.
60. For example words in the application may indicate that the individual might be terminally ill such as palliative care. It is the case manager's responsibility to investigate to ensure special rules are applied if applicable.
61. If the case manager identifies that a non-SRTI individual may be eligible under SRTI rules they must alert the practitioner. If the practitioner agrees, the practitioner must contact the RMP or RN and ask whether the individual meets the terminal illness definition.
62. If the RMP or RN confirms that the individual is terminally ill they can either:
- return a BASRiS form to Social Security Scotland
 - confirm the individual is terminally ill over the telephone with the practitioner and return a BASRiS form to Social Security Scotland.

Moving from Child Disability Payment to Adult Disability Payment

63. An individual in receipt of Child Disability Payment under special rules for terminal illness will not need to apply for Adult Disability Payment. We will make a determination without application using the information we have for the Child Disability Payment award. Where we do this the Adult Disability Payment award will commence the day after the Child Disability Payment award is ended.
64. This determination without application will be done if the individual has reached 16 and they have made a request to be moved to Adult Disability Payment.¹
- 1 ADP regs, reg. 59(1)(a)*
65. When the individual reaches 18 we will do a determination without application for Adult Disability Payment unless the individual has told us they do not want to move to Adult Disability Payment.¹
- 1 ADP regs, reg. 59(1)(b)*
66. If the individual has told us they do not want to move to Adult Disability Payment they will remain on Child Disability Payment indefinitely.

1 CDP regs, reg. 4(1B)(a)

67. Where a determination without application for Adult Disability Payment is made for an individual in receipt of Child Disability Payment under terminal illness rules no clinical judgment is required.¹

1 ADP regs, reg. 59(2)(a)

68. The new Adult Disability Payment award will start on the day the determination without application is made and no backdating will be required.¹

69. 1 ADP regs, reg. 59(2)(b)

Change of Circumstances

70. 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:

- if the individual is living in alternative accommodation
- a change in diagnosis meaning the individual is no longer considered to be terminally ill

71. If an individual is terminally ill changes to the appropriate value of payment where the individual is in alternative accommodation follow the standard Adult Disability Payment rules for alternative accommodation.

72. Payment continues for the daily living and mobility components when the individual is in a hospice, is terminally ill and Social Security Scotland have been informed that the individual is terminally ill¹

1 ADP regs, reg. 29(1)

Changes when an individual already entitled to ADP becomes terminally ill

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

74. This could happen in two ways:

- the individual informs Social Security Scotland that they have become terminally ill.
- a BASRiS form is received by Social Security Scotland for an individual currently in receipt of ADP.

75. On receipt of a BASRiS form, or following verbal BASRiS confirmation with the RMP or RN, the individual's award becomes subject to the special rules on terminal illness. Social Security Scotland will make a determination without application so that an individual under state pension age at the time of the

clinical judgement receives the enhanced rate of the daily living component and the enhanced rate of the mobility component. There is no review date.

76. If we receive a BASRiS form for someone in receipt of Adult Disability Payment after the individual has reached state pension age but which is dated before the person reached state pension age then the limitations to any increase in the mobility component do not apply.¹ This is because they became eligible for Adult Disability Payment under special rules on the date of the clinical judgement which was before they reached state pension age. They would be awarded the enhanced rate for both the daily living and mobility components.

1 ADP regs, reg. 25(5)

77. If the individual is over state pension age when they inform us that they are terminally ill and when the clinical judgement is made then they receive the enhanced rate for the daily living component. The restrictions on the mobility component where the individual is over state pension age will apply. This means for their new award the rate of the mobility component cannot be increased.

78. The new level of entitlement begins from the earlier of:

- the date that the RMP or RN made the clinical judgement that the individual meets the terminal illness definition. Unless Social Security Scotland received this judgment on the phone this will be the date the BASRiS was completed
- the date Social Security Scotland were notified by the individual that they were now terminally ill¹.

1 ADP regs, reg. 26(4)(a)(b)

Changes in award due to new information received

79. 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 rate of ADP payable, or cause entitlement to ADP to end.

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

- whether payment of assistance can continue
- which components of the assistance they receive
- at which rate of each component they receive the assistance.

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

81. Examples of relevant changes in circumstances include:

- a change in prognosis
- admission to publically funded residential care
- change to immigration status
- official error

- moving from Scotland to another part of the UK.

For example, a terminally ill individual over 18 years admitted to publically funded care home (not a hospice) would:

- stop being paid the daily living component after 28 days in residential care
- still be paid the mobility component.

82. An individual reports that there has been a change in their prognosis and they are no longer terminally ill. A case manager could request further information to establish the individual's correct level of entitlement. Then a determination without application could be made setting out the individual's new level of entitlement applying the normal rules.

Re-determinations and Appeals

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

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

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

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

86. 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 ADP Regs, reg. 54(1) and Social Security Scotland Act s 62

Re-determination of a successful application

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

Example: re-determination of award date

An individual's application was received on 10 March. Following this a BASRiS form for the individual is received which has a date 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 ADP should match the date on the BASRiS form.

The case manager carries out a re-determination and decides that the new award start date is 1 March. The individual should be paid any arrears of ADP between 1 and 10 March.

Re-determination of an unsuccessful application

88. An individual or their representative can ask for a re-determination of an unsuccessful SRTI application. An individual's SRTI application 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.

89. If the individual does not meet the conditions for the 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]