

Special Rules for Terminal Illness (SRTI)

Index

- Introduction
- Need for Discretion
- Special Rules for Terminal Illness
- Eligibility
- Supporting information for SRTI
- Applications from a third party
- Date of Award
- Applications not made under SRTI
- Change of Circumstances
- Re-determinations and Appeals

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 Child Disability Payment (CDP).
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.

1 CDP regs, reg. 15(9)(a)

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)

Need for Discretion

8. 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(1)

9. 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.

10. 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.

11. 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.

12. This is because:

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

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

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

15. 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, and
- The Tribunal is satisfied that it is in the interests of justice and proportionate to give such a direction ¹

16. 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: application where harmful information has been withheld

Janosch’s parent has applied for CDP on Janosch’s behalf but does not tell Social Security Scotland that the child has a terminal illness. Janosch’s grandparent tells Social Security Scotland that:

- the parent does not know that the child is terminally ill **and**
- it would be harmful for the parent to know their child is terminally ill.

A Social Security Scotland practitioner contacts the RMP or RN named in the application to ask them whether Janosch meets the terminal illness definition and a BASRiS form is appropriate. This includes establishing whether the RMP or RN has withheld any information from the parent because they have determined it would be likely to cause serious harm to their mental or physical health.

The RMP or RN sends a BASRiS form which confirms that the parent does not know that their child is terminally ill because the RMP or RN has withheld this information. Social Security Scotland communicates with the parent who applied for CDP making no reference to terminal illness.

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

17. 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 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. This means eligibility for the care component can begin from birth and the individual does not need to have reached 3 months of age.⁵

1 SS (S) A 2018, Schedule 5, paragraph 10

2 CDP regs, reg. 5(10)

3 SS (S) A 2018, Schedule 5, para. 9 and CDP regs, reg. 15(2)(a)

4 SS (S) A 2018, Schedule 5, para. 9 and CDP regs, reg. 15(2)(a)

5 CDP regs reg 4 (1A)

Components and Rates

18. 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.

19. CDP has two components: the care component and the mobility component. The care component has three rates (lowest, middle, highest) and the mobility component has two rates (lower, higher).

20. Individuals who are terminally ill who qualify for CDP automatically get the highest rate of the care and higher rate of the mobility components¹.

1 CDP regs, reg. 15(1)(a) and (b)

21. Individuals under three years old who have a terminal illness from birth (confirmed by the clinical judgement of an RMP or RN for example on a BASRiS form) receive the highest rate for the care component (from birth)¹. They will not receive the mobility component until they reach age 3.

1 CDP regs reg 4(1A)

2 CDP regs, reg. 15(1)(b)

22. When an individual has an award of CDP under SRTI and is about to turn 3 years old, a case manager will carry out a determination without application, and make a decision that the individual is entitled to the higher rate of the mobility component from the child's third birthday.

23. When an individual who has an award of CDP under SRTI is approaching 18 years they would be contacted to initiate a transfer to ADP using a determination without application. A CDP award would be able to continue in the instance that we do not receive confirmation from the client that they would like to move to ADP.¹

1 CDP reg 4(1B)(a)

Notification of changes in circumstances

24. 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 CDP regs, reg. 5

Eligibility

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

- meet certain residence and presence criteria
- 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

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 CDP can be made by either:

- the parent, of a terminally ill child or the young person if they have reached age 16
- 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 other than parent

Michael, aged 6 is terminally ill. His doctor has completed a BASRiS form and explained his terminal diagnosis to his parents. Michael's grandfather completes an application for Michael. All communication is with the Michael's parent named on the application form.

Supporting information for SRTI

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

29. 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.

30. 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 CDP regs, reg. 15(9)(a)(i) and (ii)

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

1 CDP regs, reg. 5

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

33. 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 CDP regs, reg 15(9)(b)

34. Normally a healthcare professional in an EEA state 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 CDP regs, reg. 15(8)

35. 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.

36. 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.
37. The case manager does not need to wait for the electronic or paper BASRiS form to arrive.

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

Ahmed's parent submits an application for CDP under special rules because Ahmed has a progressive disease. There is no accompanying BASRiS form.

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

If the RMP or RN determines that Ahmed 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 Ahmed does not meet the terminal illness definition his parent 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 a CDP award under normal rules. If so further information will be requested from the parent.

38. 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

39. Applications under SRTI rules can be submitted by a third party. There are no restrictions on who can submit a third party SRTI application.
40. 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.
41. 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.
42. The individual does not have to sign the application form for assistance under SRTI. The individual for a CDP application will be the child but a parent / guardian / appointee of the child will be acting on their behalf. Where the individual is 16 or 17 years and has chosen to manage their award themselves they are the individual.
43. The parent of the child 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.
44. A third party can make an initial application. However, all further communication must be with either the:
- parent of the child who is terminally ill
 - person who is terminally ill
45. There are a number of ways all individuals can receive the support of a third party representative in their interactions with Social Security Scotland.
46. This is not a legal representative but a person the individual has nominated to support them.
47. 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.
48. A third party representative could continue to support the individual in their interactions with Social Security Scotland.
49. Third party representatives are available to all individuals but are likely to be of particular benefit to SRTI individuals.

Example: third party application

Paul's son Fergus is terminally ill. A Macmillan nurse involved in Fergus' care asks Paul if he would like her to submit an application on his behalf for CDP for Fergus.

Paul agrees and the nurse submits the application.

In completing the application the nurse needs to confirm that she has Paul's consent on behalf of Fergus. All future communication is between Social Security Scotland and Paul.

Date of Award

50. 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
 - 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).

This date can be no earlier than the date the CDP Regulations commence.

1 CDP regs, reg. 15(3)(4)

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

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

51. 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.

52. 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.

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

54. If the terminal illness diagnosis is confirmed the date the award will commence is backdated to a maximum of 26 weeks¹.

1 CDP regs, reg. 15(5)

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 a BASRiS that was signed 30 weeks before the date it receives the application. 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 higher rate for care was uprated on 1 April. Payments for the weeks prior to 1 April will be calculated on the rate prior to the uprating. Payment for any weeks after 1 April will be calculated at the uprated rate.

55. Entitlement to disability benefit cannot precede the date the relevant legislation came into effect. Social Security Scotland can only accept a BASRiS for CDP if the date on the BASRiS is on or after the date Social Security Scotland begins delivering CDP.

Application not made under SRTI

56. 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.

57. 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.

58. 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.

59. 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.

Change of Circumstances

60. 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. 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

61. Payment of the care component stops on the day after the individual has been resident in a care home or residential educational establishment for 28 days¹. This is because the cost of meeting the individual's care needs are already being met by public funds. The mobility component will continue to be paid in these circumstances.

1 CDP regs, reg. 17(2)

62. Where the cost of any time spent in a care home or residential educational establishment is met:

- entirely by the individual
- partly by the individual and partly by someone else (other than a local authority)
- entirely by someone else (other than a local authority)

the individual's entitlement to be paid the care component does not stop, regardless of how long the individual is resident there¹.

1 CDP regs, reg. 17(4)

If an individual's entitlement to CDP begins whilst they are resident in a care home or residential educational establishment, the individual is not entitled to be paid the care component until the day they leave¹.

1 CDP regs, reg. 20(2)

63.

64. Payment continues for the care and mobility components when individual is in a hospital or hospice¹.

1 CDP regs, reg. 15(2)(b)

Changes when an individual already entitled to CDP becomes terminally ill

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

66. 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 CDP.

67. 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:

- the individual receives the highest rate of the care component and the higher rate of the mobility component (where there is a mobility component – for CDP the child must be 3 years old). there is no review date

68. 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 CDP regs, reg. 15(3) and reg. 15(10)

69. When calculating any increased award an individual was entitled to for a previous period following a subsequent determination we must consider the value of the entitlement rather than the amount paid.¹

1 CDP regs reg 15(10) and reg 28 (2A)

Changes in award due to new information received

70. 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 CDP payable, or cause entitlement to CDP to end.

71. 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.

72. 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 admitted to publically funded residential care would:

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

73. 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.

74. If an individual dies, Social Security Scotland makes a payment equivalent to the payments the individual received for the 8 weeks of CDP prior to the date the individual dies¹.

1 CDP regs, reg. 23(7)

Re-determinations and Appeals

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

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

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

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

78. 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 CDP Regs, reg. 37(1) and Interpretation and Legislative Reform (S) Act 2010 s 26 (5)

Re-determination of a successful application

79. 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

Guillaume's application was received on 15 June. Following this a BASRiS form for them is received which has a date of 7 June.

The award was incorrectly processed to have a start date of 15 June.

Guillaume's parent requests a re-determination because the start date of their award of CDP 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 7 June. Guillaume should be paid any arrears of CDP between 7 and 15 June.

Re-determination of an unsuccessful application

80. 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.

81. 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.