



**GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS  
ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND (BASRiS) FORM  
FOR TERMINAL ILLNESS v1.0**

**ADVICE FROM THE CHIEF MEDICAL OFFICER**

**THE SCOTTISH GOVERNMENT**

**July 2021**

## GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND (BASRiS) FORM FOR TERMINAL ILLNESS

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## 1. EXECUTIVE SUMMARY

Following the Scotland Act 2016, three disability benefits have been devolved to Scotland and will become the responsibility of Scottish Ministers. These benefits are Child Disability Living Allowance (DLA Child), Personal Independence Payment (PIP) and Attendance Allowance (AA). The new Scottish replacements of these 3 benefits will be administered by Social Security Scotland with different rules. They will be called Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment. Other benefits, such as Universal Credit, have not been devolved and continue to be administered on a UK basis, by the Department for Work and Pensions (DWP), following existing rules and definitions.

People of all ages who live in Scotland with terminal illness are able to apply for disability benefits under special rules resulting in the fast tracking of their application and higher rates of assistance. This guidance sets out the new rules for accessing those Scottish replacements of the 3 disability benefits where the potential recipient is terminally ill (Benefits Assessment under Special Rules in Scotland (BASRiS)) using a new definition of terminal illness for social security purposes.

This guidance provides a framework to support those making a clinical judgement about terminal illness i.e. doctors and nurses who provide care for people towards the end of life in a professional capacity. The guidance is also relevant to others with an interest or involvement in the care of people who may be approaching the end of life and/or involved in advising on social security benefits. It will also be of interest and relevance to people who are themselves approaching the end of life, plus their family and carers.

New Scottish legislation changes the definitions and rules surrounding terminal illness for the purpose of access to the devolved benefits. This means that there will be no limit set on how long a patient has left to live before their condition is considered “terminal”.

The terminal illness definition that the Scottish Ministers use when making Disability Assistance Regulations under the Social Security (Scotland) Act 2018 is:

*An individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the (Chief Medical Officer’s (CMO) guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual’s death.*

An appropriate healthcare professional is defined as a registered medical practitioner or registered nurse who meets the requirements set out in the regulations.

This guidance supports clinicians to interpret and apply this definition consistently. To meet the definition the individual should have an illness

a) that is advanced and progressive or with risk of sudden death, AND;

b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;

c) that is leading to an increased need for additional care and support.

Notable features of this definition of terminal illness, which are different from some other existing definitions, are:

- It is based on a clinical judgement, using a range of largely clinical indicators.
- There is no requirement to make a prognostic judgement about how long somebody will live.
- There is no requirement to assess individual care needs.
- It goes beyond cancer to include all diseases and conditions that are judged to be terminal. Examples include: organ failure (respiratory disease, heart and vascular diseases, kidney disease, liver disease); neurological diseases (Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis); Stroke; Frailty with one or more co-morbid diseases; Dementia; rare diseases; combinations of diseases with conditions.
- It applies to all irrespective of criteria such as age and residency status, provided they live in Scotland or fall into one of the statutory exceptions from the requirement to live in Scotland.

There are many diseases, which may lead to a patient's death in the future such as diabetes or COPD but where the diseases are not at a stage that means the patient requires fast tracked benefits. This guidance is not intended for such cases.

The form to certify that a patient is terminally ill, enabling them to apply for benefits under special rules is included in this guidance. This form replaces the DS 1500 for the Scottish replacement of benefits listed above that have been devolved to Scotland. Those already on DS 1500 do not require a BASRiS form to be completed. Their entitlement will be automatically recognised and transferred to the benefits under the Scottish system.

Section 2 is a flowchart illustrating the different processes through which an individual presenting with progressive disease may pass, depending on their circumstances and whether or not they meet the new definition. It should be remembered that a patient who is not eligible under the special rules is still able to apply for benefits and undergo assessment in the usual way.

Section 3 is a table summarising the differences between the current UK rules for terminal illness benefits ("DS1500") and the new approach to disability benefits which have been devolved (Benefits Assessment under Special Rules in Scotland (BASRiS)).

Sections 4-6 provide more detail on the aim, purpose and principles of BASRiS.

Section 7 is a key section providing more detail on how doctors and nurses must approach the clinical assessment of terminal illness.

Section 8 lists the factual information which will be required when documenting a clinical assessment of terminal illness on a BASRiS form.

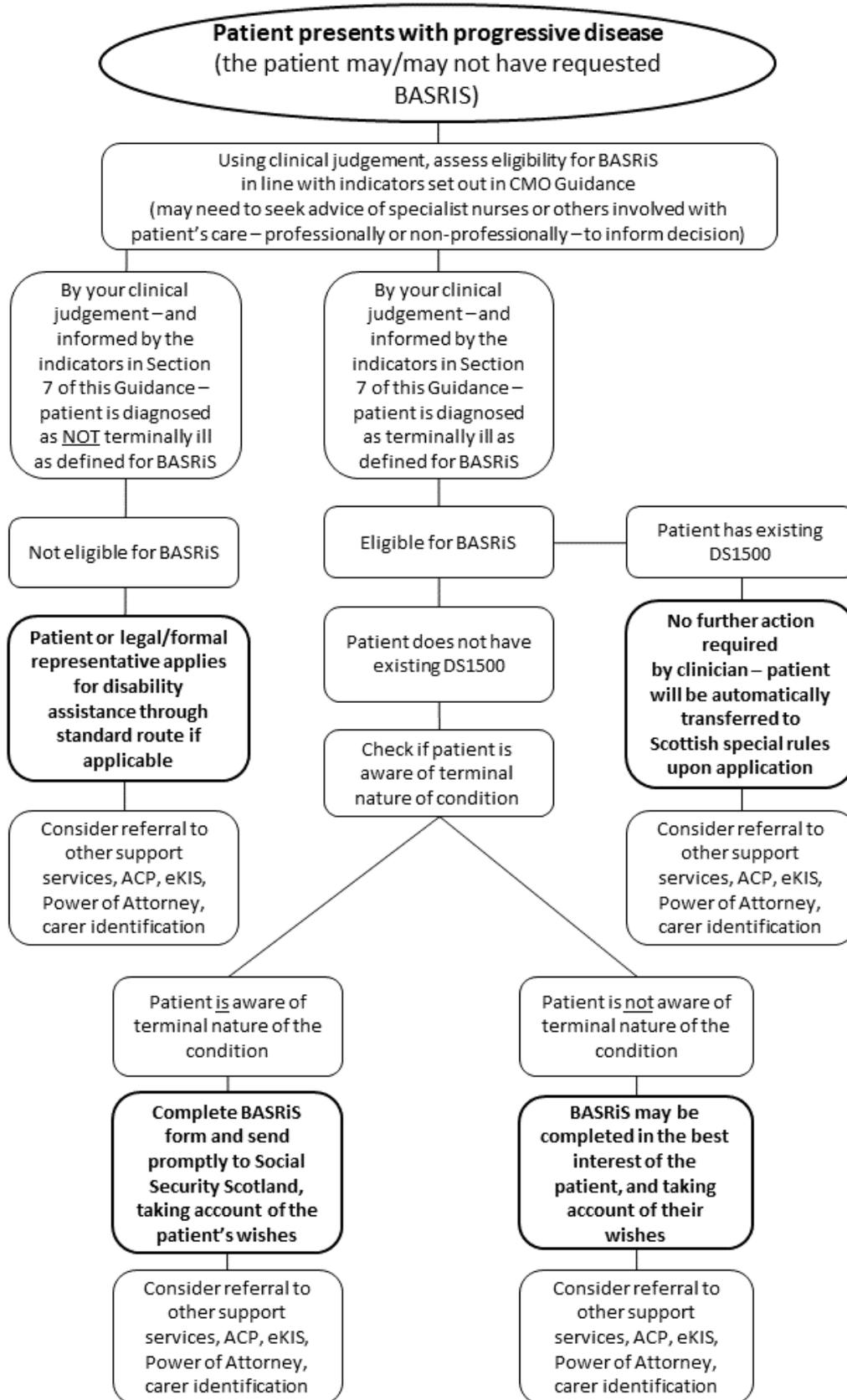
Section 9 provides information on how to apply this guidance in the case of babies, children and young people.

Section 10 sets out which doctors and nurses are eligible to make a clinical assessment of terminal illness for the purpose of BASRiS.

Section 11 provides guidance on handling the sensitive communications with individuals and their families/carers which is required throughout the BASRiS process.

There are nine annexes (A to I) which provide a range of background information and practical resources. These are signposted at relevant points in the body of the guidance. Annex B contains resources designed to help in reaching a clinical judgement as to whether an individual meets the definition of terminal illness. Annex C contains some case-based worked examples involving adults and children of how the definition would apply to different individuals.

## 2. FLOW CHART FOR ELIGIBILITY FOR BASRIS FORM COMPLETION



**DIFFERENCES BETWEEN THE REQUIREMENTS FOR BASRiS AND DS 1500 FORMS**

**The Table below provides the differences between the 2 systems**

<b>Requirements</b>	<b>BASRiS (when Scotland's replacement benefits commence)</b>	<b>DS 1500 (current UK rules used by DWP)</b>
Definition of terminal illness	It is the <u>clinical judgement</u> of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death.	A progressive disease where death as a consequence of that disease can reasonably be expected <u>within 6 months</u> .
Time limit	No time limit	Likely to die within 6 months
Qualifying period	None	None
Review period	No review period	Review after 3 years
Benefits	Automatic award to the highest rate of <u>assistance that they are entitled to: Child Disability Payment Adult Disability Payment and Pension Age Disability Payment</u>	Automatic award of the highest rate for <u>care only</u> under the relevant benefit at present: PIP, DLA and AA as well as Employment Support Allowance (ESA) and Universal Credit (UC).
Completed by	Registered Medical Practitioners and Registered Nurses	Medical Practitioners or specified Specialist Nurses
Interaction between BASRiS and DS 1500	Individuals in receipt of BASRiS will need to meet the DWP definition if claiming ESA or UC. Where a client already has a BASRiS form the DWP can use the information, as part of their suite of medical information, to determine whether the individual meets their definition and is therefore eligible for the reserved benefit under the DWP rules.	Individuals already In receipt of DS1500 will be automatically eligible under BASRiS.

**Definitions**

**BASRiS**

The terminal illness definition under the Social Security (Scotland) Act 2018 is:  
*"An individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the (Chief Medical Officer's (CMO) guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death."*

## DS 1500

Terminal illness for the purposes of DS 1500 is defined in UK Social Security legislation as:

*“a progressive disease where death as a consequence of that disease can reasonably be expected within 6 months”.*

### 3. BACKGROUND

The Scotland Act 2016 gave Scotland new powers relating to social security, including responsibility over certain benefits ([Annex E](#)).

These powers have been used to create a Scottish Social Security system based on dignity, fairness and respect, which will help to support those who need it, when they need it. This includes improving benefits for disabled people and people with ill health, as well as confirming that on the infrequent occasions that assessments are required, they will not be carried out by the private sector.

The Social Security (Scotland) Act 2018 confirms that there will be no limit set on how long a patient has left to live before their condition is considered "terminal" ([Annex G](#)). It is for Registered Medical Practitioners (RMPs) and Registered Nurses (RNs) to use their clinical judgement to decide whether the illness is terminal, enabling their patient to apply for disability assistance under special rules, where appropriate. This will allow the patient's claim for disability assistance to be processed differently, under special rules, resulting in the fast tracking of their application and entitlement to the highest rates of the components (care and/or mobility) relevant to the benefit.

In this context, it is expected that the RMPs and RNs involved in the diagnosis of terminal illness:

- must have appropriate skills, knowledge and experience to undertake the role and;
- must be involved with the diagnosis and / or care of the patient and;
- must be acting in their professional capacity and;
- must work in accordance with a clinical governance framework and the requirements of your employers and/or contractual arrangements and;
- must hold current registration with the General Medical Council or the Nursing and Midwifery Council.

(More information can be found in the online Frequently Asked Questions <https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-frequently-asked-questions><sup>1</sup>)

The evidence you provide through BASRiS will support Social Security Scotland to make a decision about entitlement to disability benefits under special rules.

Your responsibility is to use your clinical judgement to diagnose whether you consider the individual's condition to be terminal, according to the new definition, i.e. *An*

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<sup>1</sup> <https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-frequently-asked-questions>

*individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, (having had regard to this CMO guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death.*

#### **4. LEGISLATION**

Special Rules in Scotland has 4 components:

- There is no qualifying period. An individual is not required to have the condition for any length of time before they are eligible under special rules.
- Once verification has been given that the person is considered to have a terminal illness, for the purpose of entitlement to disability assistance, there is no requirement for an individual to undergo any further assessment to establish that a person has a terminal illness
- Awards will be calculated, at the latest, from the date of application by the patient
- Patients who qualify under special rules will be automatically entitled to the maximum amount of award of the benefit they are entitled to

The Social Security Principles, with the underpinning legislation for the special rules are set out in ([Annex G](#)).

#### **5. AIM**

The aim of this guidance is to enable RMPs and RNs to use their clinical judgement to determine whether their patient is terminally ill, for the purpose of entitlement to disability assistance. Through the completion of a BASRiS form, your evidence will support your patient's application for disability assistance to be processed differently, under special rules. Social Security Scotland may require further information from RMPs and RNs signing the BASRiS form, where the content is not explicit or legible enough. With this in mind, the document provides guidance to support and assist you in making these difficult decisions. It will also enable you to explain and provide a clear rationale for making those decisions made on clinical grounds, if patient, carers, family, or others have any queries.

The process for diagnosing terminal illness for the purposes of applying for Scottish equivalents of disability assistance, as laid out in this Guidance, applies to all – irrespective of criteria such as age and residency status, provided they live in Scotland (or fall into one of the statutory exceptions from the requirement to live in Scotland). This includes people with no fixed address or who are homeless. The only exception is those who are subject to immigration status. However, there is no requirement for RMPs and RNs to determine these factors, as these checks will be undertaken by Social Security Scotland.

#### **6. BASRiS PURPOSE AND PRINCIPLES**

The purpose of the BASRiS form is to provide evidence about whether, in your clinical judgement, the condition is “terminal” and therefore the individual requires expedited access to disability assistance. This will provide evidence of eligibility to disability

assistance under special rules. It is not for you to assess the type of disability benefit that your patient is eligible for or undertake a formal functional assessment. In addition, the purpose of the clinical assessment for these benefits, in this instance, is not to provide care. However, those patients who are eligible for these benefits could also be in receipt of other care and support services or signposted to these services where appropriate.

By recording your clinical judgement on the BASRiS form, your patient will be able to access much needed additional support at the time of their greatest need. The disability benefits are likely to enable them to have the quality of life that they seek, for example: meeting additional costs of care or travel, and providing the ability to visit places or people that they hold dear.

#### *Principles:*

- The process should be fair and seen to be fair and transparent to the RMPs RNs, other professionals and the public.
- The process should support an individual when they are terminally ill (see definition set out in [Section 7](#)), reducing unnecessary distress wherever possible. It may also improve the quality of life of carers and those close to the individual.
- Receipt of the new Scottish benefits Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment, may enable access to relevant housing, and health and social care support for the individual. The benefits may assist in the access to benefits for the patient's carers.
- The process may also require an application by the individual or a third party acting on their behalf for the relevant disability assistance, if this is not already in place.
- The clinical judgement of terminal illness enables the provision of assistance for the added costs of the disability. The benefit is not "income support" and is not means tested.
- The process of making the clinical judgement should be consistent with this guidance, despite the decisions varying according to individual circumstances.
- Social Security Scotland may require further information from RMPs and RNs signing the BASRiS form, where the content is not explicit or legible enough to process the application.
- Even if the decision that the patient is not deemed eligible for the fast tracking of benefits assistance under special rules, they can be assessed by Social Security Scotland using the standard application route.

## **7. CLINICAL ASSESSMENT OF TERMINAL ILLNESS**

The Social Security (Scotland) Act 2018 states that regulations are to make clear that: *an individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, (having had regard to the CMO guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death.*

It is important to note that this definition goes beyond cancer to include all diseases, including those associated with other conditions, that are judged to be terminal by an RMP and RN. Examples include: organ failure (respiratory disease, heart and vascular diseases, kidney disease, liver disease); neurological diseases (Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis); Stroke; Frailty with one or more co-morbid diseases/conditions; Dementia; and rare conditions or diseases. This list is not exhaustive. In addition, individuals' eligibility for BASRiS also could be established based on a combination of diseases with conditions.

Your patient should display all of the following indicators:

- a) an illness that is advanced and progressive, or with risk of sudden death, AND;
- b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;
- c) that is leading to an increased need for additional care and support.

There are a number of tools, which can be used to assist you in the process of making your clinical assessment of terminal illness, and these are given in [Annex B](#).

There are many diseases, which may lead to a patient's death in the future such as diabetes or COPD but where the diseases are not at a stage that means the patient requires access to disability assistance under special rules for terminal illness. This guidance is not intended for such cases because expedited access to benefits is unnecessary.

Accurately predicting when someone may die is known to be difficult and imprecise. Estimating prognosis is also recognised to be challenging. The clinical judgement becomes more challenging the further ahead you are asked to predict a patient's death.

Certainty is not required.

A GP on average will be involved in approximately 20 deaths/2000 patients/year. Of these, 2 are likely to be Sudden Unexpected deaths; around 5 deaths will be due to Cancer; around 6 deaths will be due to Organ Failure; and around 7 deaths will be due to Dementia, Frailty, and Decline ([Murray SA & Sheikh A. Palliative Care Beyond Cancer: Care for all at the end of life. BMJ 2008;336:958-9](#)).<sup>2</sup> The clinical judgement that you are being asked to make is about the patient's overall condition, and from a basket of indicators. At the time of making the decision, in addition to the diagnosis of the terminal disease, you should also take account of the wider circumstances affecting their ability to cope with undertaking activities of daily living.

The assessment and judgement should be made on clinical grounds and be based on suitable clinical expertise and opinion, as well as the experience of your patient and their carers or family. Any additional information gathered about the patient's condition and circumstances, may be of assistance to you and other colleagues in assessing and planning to meet other health and care needs. The information you gather may

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<sup>2</sup> <https://www.bmj.com/content/336/7650/958.1.short>

also help you to provide a clear rationale for making the decision for or against eligibility for BASRiS, in the event of any queries or disagreement from the patient, carers, family, and/or others.

Some tools to help you to improve the consistency in the process of making the clinical judgement of terminal illness are attached in [Annex B](#).

Social Security Scotland may seek information from the RMP and RN signing the BASRiS form, depending on explicitness, legibility and clarity of the content.

Some worked examples are included in [Annex C](#).

An information leaflet for professionals and a similar leaflet for individuals who are terminally ill and those who support them have been developed by Social Security Scotland with input from stakeholders, which can be shared widely. Links to these can be found in [Annex H](#).

The differences between DWP criteria for DS 1500 and the BASRiS will require to be handled sensitively, particularly if a patient is accessing both devolved and reserved benefits. The differences between BASRiS and DS 1500 are laid out in [Section 2](#). It is important that you are aware that there are other legislative definitions of terminal illness (e.g. Carers (Scotland) Act 2016.). However, these should not be used to assess eligibility for BASRiS

## **8. FACTUAL INFORMATION THAT MUST BE INCLUDED**

The BASRiS form is based on factual information, and should contain details of:

- Community Health Index (CHI) number of the individual
- Your General Medical Council (GMC) or Nursing and Midwifery Council (NMC) number and official work contact details including telephone number (not your personal number)
- Affirmation that you are providing the information to the best of your knowledge and belief and that you have been professionally involved in the diagnosis and/or care of the patient and had access to the relevant records. This includes doctors or nurses taking over the care of the patient.
- Diagnosis of the main disease/s and other relevant associated conditions (in some cases there may be no formal explicit diagnosis e.g. you may have to record the diagnosis as “neurological disease” without specifying which neurological disease in babies, children, young people or adults)
- **Clinical features of the disease (causing the terminal illness) which indicate a severe progressive condition (examination findings and results of investigations including staging if appropriate)**
- **Relevant treatment including response and planned treatment/interventions that may significantly alter the prognosis**
- **Whether the patient is aware of their condition and/or prognosis**
- **If unaware, the name and address of the patient’s legal representative requesting the form or aware of the form being completed**

- Consent from patient and/or their representative to share the information with Social Security Scotland, and noted in the patient's clinical records
- Whether carers' views have been taken into account

## 9. BABIES, CHILDREN AND YOUNG PEOPLE

This guidance is equally applicable to babies, children and young people with life threatening or life limiting diseases or illness.

Children and young people may have particular needs. Their views, if they have mental capacity, need to be considered alongside those of their parents, carers and family, in accordance with the [Getting it Right for Every Child \(GIRFEC\)](#)<sup>3</sup> approach.

Children and young people have rights, which should be respected. This includes taking into account their views and respecting their confidentiality.

Appropriate language and forms of non-verbal communication should be employed, noting that conversations with children and young people may be very challenging when considering issues related to likely end of life care, not least, as many professionals do not undertake these on a regular basis.

The Social Security (Scotland) Act 2018 recognises the importance of inclusive communication. It states that:

*“communicating in an inclusive way’ means communicating in a way that ensures individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet each individual’s needs.”*

<http://www.legislation.gov.uk/asp/2018/9/enacted><sup>4</sup>

Identifying the best interests of babies, children and young people is often not easy, and may be complicated by legal and ethical issues, as well as issues of consent and capacity.

<https://learning.nspcc.org.uk/research-resources/briefings/gillick-competency-and-fraser-guidelines/><sup>5</sup>

Child protection issues also need to be considered in the usual way, as some individuals may be a danger to the child or young person.

The trajectory of diseases and illness in babies, children and young people, may be different to that in adults.

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<sup>3</sup> <https://www2.gov.scot/Topics/People/Young-People/gettingitright>

<sup>4</sup> <http://www.legislation.gov.uk/asp/2018/9/enacted>

<sup>5</sup> <https://learning.nspcc.org.uk/research-resources/briefings/gillick-competency-and-fraser-guidelines/>

Specific issues related to neonatal conditions need to be considered, such as, following premature birth, birth injuries, the diagnoses of congenital abnormalities and metabolic diseases.

Children and Young People may have different support mechanisms e.g. young people may relate more to their peers.

You may wish to discuss the completion of a BASRiS form with the specialist involved in the care of the child or young person, or another specialist in this area. A reference point may be through discussion with colleagues at Children's Hospices across Scotland (CHAS): <https://www.chas.org.uk/>.

## **10. ELIGIBILITY TO COMPLETE THE FORM**

An RMP or RN who meets all 5 criteria can complete the BASRiS form. The RMP or RN:

- must have appropriate skills, knowledge and experience to undertake the role and;
- must be involved with the diagnosis and / or care of the patient and;
- must be acting in their professional capacity and;
- must work in accordance with a clinical governance framework and the requirements of your employers and/or contractual arrangements and;
- must hold current registration with the General Medical Council or the Nursing and Midwifery Council

This is in contrast to the DS 1500 form, which can be completed by certain types of specialist nurses. Currently, the Scottish legislation only allows Registered Medical Practitioners and Registered Nurses to take responsibility for signing the BASRiS form for devolved benefits. Other professional groups are not eligible to sign the BASRiS form at this stage. However, RMPs and RNs may wish to consult and seek the advice of the wider healthcare and non-healthcare staff involved in the care and support of the patient where relevant, in addition to seeking the views of the patient's informal carers, when completing the form.

This may include nurses and other clinical professionals, social workers, care workers, housing officers and others.

On some occasions, Social Security Scotland may receive a completed form from an applicant, stating that the application is under Special Rules for Terminal Illness without submitting a BASRiS form. In this instance, a Social Security Scotland (clinical) Practitioner may make telephone contact with the RMP or RN nominated on the form by the applicant and check eligibility of their patient to receive a BASRiS certificate. If the answer is "yes", then the application will be processed and payment made to the claimant. Following this the RMP or RN will complete and send a BASRiS form for their patient and keep a copy for the patient record. Social Security Scotland would expect to receive the form within a month; if it has not been received they could follow this up. The RMP or RN will only receive a payment if eligible to claim fees for completion of the form, when Social Security Scotland receive a completed and signed BASRiS form and the Fee Payment Form. If the answer is "no", then the applicant can choose whether to agree to Social Security Scotland processing the application under normal rules or contact the RMP or RN to discuss their clinical condition.

Where the individual who is terminally ill meets the residence and presence conditions for disability assistance but is currently living in an EEA state, Switzerland or Gibraltar then appropriate healthcare professional includes a doctor or nurse who has equivalent qualifications to a registered medical practitioner or registered nurse, in an EEA state, Switzerland or Gibraltar. They must meet the 5 criteria set out above with the exception of the fifth. Instead the doctor or nurse must be a member of the professional body equivalent to the General Medical Council or Nursing and Midwifery Council in that EEA state, Switzerland or Gibraltar.

## **11. COMMUNICATION AND CONSULTATION WITH OTHERS (INCLUDING CARERS)**

### **Communication with other healthcare professionals**

You may wish to take the opportunity to seek the views of other professional colleagues involved in the care of the individual. You may also wish to share the information that a BASRiS form has been completed with other relevant professional colleagues, once completed.

### **Communication with your patient, carers, and family**

You should raise the issue of BASRiS when appropriate, rather than wait for the patient, their carer or family to raise it with you e.g. it would be beneficial to consider the provision of BASRiS form at relevant interactions, such as when agreeing an electronic Key Information Summary (eKIS) and an Anticipatory Care Plan (ACP) recommended by the Healthcare Improvement Scotland's Scottish Anticipatory Care Programme.

In some cases a patient may already be aware of BASRiS and may approach the RMP or RN, asking them for a BASRiS form.

You should have a conversation with informal and formal carers, wherever possible and relevant e.g. where the individual or their legal representative has given permission, and where this will assist a clinical judgement to be made without resulting in additional unnecessary delays. Your approach should be sensitive to their needs and beliefs. Carers and family members may be able to provide evidence and examples of the rapidity of deterioration of the condition, which may help you to make a decision.

Depending on what the patient already knows, it can be a difficult conversation for clinicians and their patients, and/or family and carers. A very imprecise prediction of prognosis may cause distress to the patient, their carers or family.

There may not be the opportunity to have several conversations over time with patients and those close to them.

Be mindful that some patients may wish to know everything about the prognosis of their condition and others may not want to have the conversation at all. In addition,

some patients may not be aware of their condition. Your approach can have a long lasting effect on the individual and their carers and families.

Please consider the following links, which provide advice and guidance on initiating sensitive and difficult conversations:

<https://gmcuk.wordpress.com/2016/05/13/handling-difficult-conversations-ten-top-tips/><sup>6</sup>

<http://www.sad.scot.nhs.uk/media/16017/transcript-of-discussing-dying.pdf><sup>7</sup>

<http://www.sad.scot.nhs.uk/before-death/end-of-life-care/><sup>8</sup>

<https://www.bhf.org.uk/informationsupport/publications/living-with-a-heart-condition/difficult-conversations---talking-to-people-with-heart-failure-about-the-end-of-life><sup>9</sup>

<https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/><sup>10</sup>

<http://www.ec4h.org.uk/resources/anticipatory-care-planning-in-scotland/><sup>11</sup>

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<sup>6</sup> <https://gmcuk.wordpress.com/2016/05/13/handling-difficult-conversations-ten-top-tips/>

<sup>7</sup> <http://www.sad.scot.nhs.uk/media/16017/transcript-of-discussing-dying.pdf>

<sup>8</sup> <http://www.sad.scot.nhs.uk/before-death/end-of-life-care/>

<sup>9</sup> [Difficult Conversations | BHF](#)

<sup>10</sup> <https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>

<sup>11</sup> <http://www.ec4h.org.uk/resources/anticipatory-care-planning-in-scotland/>

## ADDITIONAL INFORMATION (INCLUDING PARTICULAR CIRCUMSTANCES)

### 1. PROFESSIONAL RESPONSIBILITIES

For RMs, your actions should be in line with your professionalism required in the [GMC's Good Medical Practice](#)<sup>12</sup> e.g. you are competent, keep your knowledge and skills up to date, you establish and maintain good relationships with patients and colleagues, are honest and trustworthy, and act with integrity and within the law. RN actions should be in line with the [NMC Code](#)<sup>13</sup> e.g. you maintain the knowledge and skills required for safe and effective practice, communicate effectively and clearly and show integrity in your practice. You should be alert to and address unwarranted variation in your assessments and decisions.

You should provide the report to the best of your knowledge and belief, on the balance of probabilities. The clinical judgement should be made by you, and supported by as much relevant information that is available to do so. Certainty is not required. Reflection on previous decisions may be able to support you to make the appropriate decisions in the future.

GMC does caution doctors, that the legal requirements should not be construed in such terms that they prevent doctors from exercising appropriate clinical judgement, or give rise to conflicts of interest, when it comes to diagnosing and managing a patient's condition. For example, any interpretations likely to incentivise doctors and/or patients to take a particular approach to the diagnosis and management of a patient's condition, which might not otherwise be seen as clinically appropriate, or of no overall benefit to the wellbeing of the patient, should be avoided. NMC requires nurses to exercise their judgement in any decision making and to uphold the values set out in the Code and in line with the laws of the country of practice.

[BMA ethical guidance](#)<sup>14</sup> and [NMC principles](#)<sup>15</sup> and [ethical guidance](#)<sup>16</sup> can also help with the consideration of relevant legal and ethical principles.

### 2. TIME TO RESPOND AND RETURN THE FORM TO SOCIAL SECURITY SCOTLAND

Once you have determined that a BASRiS form should be completed, you should complete the form promptly, with the expectation that it will be done as quickly as possible. This may be following your own knowledge of the condition and decision, or an assessment of the situation following a request by the individual, their carer or another healthcare professional involved in their care. This does not have to be via a face-to-face appointment.

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<sup>12</sup>[https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128\\_pdf-51527435.pdf?la=en&hash=DA1263358CCA88F298785FE2BD7610EB4EE9A530](https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf?la=en&hash=DA1263358CCA88F298785FE2BD7610EB4EE9A530)

<sup>13</sup><https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf>

<sup>14</sup><https://www.bma.org.uk/advice/employment/ethics/ethics-a-to-z>

<sup>15</sup><https://www.rcn.org.uk/professional-development/publications/pub-006499>

<sup>16</sup><https://www.rcn.org.uk/professional-development/principles-of-nursing-practice>

### 3. CONSENT

You need to seek and obtain valid informed and explicit consent from the patient and/or their representative, to share their personal/sensitive information securely with Social Security Scotland. You will need to keep a record of this consent as part of the clinical records you hold for the patient.

In some cases, such as in the absence of the patient's legal representative, you may need to send the BASRiS form to Social Security Scotland without the explicit consent of the patient. This would be necessary, if you believe that it is in the best interest of the patient, as disclosing the clinical information to the patient, in your view would be harmful to the patient (see section - 7 Harmful Information). If the BASRiS form has been completed and sent under these circumstances, and using the legal basis under [General Data Protection Regulations \(GDPR\)](#),<sup>17</sup> (namely that processing is necessary in the public interest), detailed records need to be kept of the reason e.g. detriment to mental and emotional wellbeing of the patient. However, you need to be aware that given the [European Convention on Human Rights](#)<sup>18</sup>, you cannot override the express wishes of the patient, where the patient has capacity to express them. In other words, where such a patient has stated that they do not wish the BASRiS form to be completed and submitted to Social Security Scotland, BASRiS form must not be completed.

The Social Security (Scotland) Act 2018 ('the 2018 Act') makes provision for formal and legal representatives to act on behalf of adults with incapacity such as:

Appointees;  
Guardians;  
Personal Acting Bodies;  
Corporate Acting Bodies; and  
Power of Attorney

However, there may be individuals who do not lack capacity but could benefit from an appointee in certain circumstances. Some individuals may prefer and agree to another person becoming their appointee during a very difficult time in their lives. Where harmful information has been withheld, Social Security Scotland will inform the client of the many ways they could be supported in their interactions with the agency and this will include the option of having an appointee to act on their behalf.

#### ***Third party Representative***

Many adults who do not fall within the definition of an adult with incapacity<sup>19</sup> and who need or want help or advice can also access it from another person or organisation (Third Party Representative) to engage with Social Security Scotland. In the majority of circumstances it will be possible for individuals to rely on common law agency arrangements to appoint another person to act on their behalf in their interactions with Social Security Scotland. This policy is specific to third party

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<sup>17</sup> <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/?q=fine>

<sup>18</sup> <https://www.equalityhumanrights.com/en/what-european-convention-human-rights>

<sup>19</sup> As defined in the [Adults with Incapacity \(Scotland\) Act 2000 section 1 para 6](#)

representatives and does **not apply to** formal representatives as listed above. This is particularly important for patients with disabilities or conditions that make it difficult for them to express themselves but who are not deemed to be an adult with incapacity, or clients for whom English is not their first language and find it difficult to communicate without an interpreter. It is important that patients who wish to do so are able to ask a third party representative to help them conduct their business with the Social Security Scotland, but that this is balanced with Social Security Scotland's obligations to protect personal information as set out in the Data Protection Act 2018.

[GMC's Guidance on Confidentiality \(10c\)](#)<sup>20</sup> also states that you must *“get the patient's explicit consent if identifiable information is to be disclosed for purposes other than their **own** care or local clinical audit, unless the disclosure is required by law or can be justified in the public interest.”* The [NMC Code](#)<sup>21</sup> states that *‘a person's right to privacy must be respected in all aspects of their care and that information may be shared about ongoing care or treatment as far as the law allows’*.

Occasionally consent may be provided by a third party appointed to act on the patient's behalf, for example:

- If the patient is incapable within the meaning of the [Adults with Incapacity \(Scotland\) Act 2000](#)<sup>22</sup>, and where the individual's estate is not being administered by a judicial factor or other person who has authority to act on behalf of the individual and is willing to do so e.g. an Appointee, a welfare or financial guardian or someone with a power of attorney.

The [Adult Support and Protection \(Scotland\) Act 2007](#)<sup>23</sup> may also be relevant in certain situations.

### **Children and Young People**

In Scotland, the general position is that a young person 16 years and above is presumed to have the capacity to enter into a transaction - [Age of Legal Capacity \(Scotland\) Act 1991](#)<sup>24</sup>. However, the Act makes clear that a person under the age of 16 years will have capacity to consent to a surgical, mental or dental procedure, on his or her own behalf, providing that the medical practitioner providing care is satisfied that the person is capable of understanding the nature and possible consequences of the procedure or treatment. No minimum age is set down, as the matter is based simply on what the medical practitioner believes to be the level of understanding of the young person. This is reflected in guidelines related to [Gillick/Fraser competence](#)<sup>25</sup>

Parental responsibility – The British Medical Association and RCN offer advice on this, but considerations also need to be made if both parents do not agree and specific

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<sup>20</sup><https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---confidentiality-good-practice-in-handling-patient-information---70080105.pdf?la=en&hash=08E96AC70CEE25912CE2EA98E5AA3303EADB5D88>

<sup>21</sup> <https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf>

<sup>22</sup> <https://www.legislation.gov.uk/asp/2000/4/contents>

<sup>23</sup> <https://www.legislation.gov.uk/asp/2007/10/contents>

<sup>24</sup> <https://www.legislation.gov.uk/ukpga/1991/50/contents>

<sup>25</sup> <https://learning.nspcc.org.uk/research-resources/briefings/gillick-competency-and-fraser-guidelines/>

considerations need to be made when a baby, child or young person has a legal guardian. Individuals who are “looked after and accommodated” have special considerations and ‘parental responsibility’ may be devolved to their local authority up to the age of 25 years.

[Parental responsibility – BMA<sup>26</sup> Parental Responsibility p10 - RCN<sup>27</sup>](#)

Children and young people may have particular communication needs and may need help to make decisions.

#### **4. ACCESS TO THE COMPLETED FORM BY INDIVIDUAL (PATIENT) OR LEGAL REPRESENTATIVE**

[The Access to Medical Reports Act 1988<sup>28</sup>](#) only applies to access to reports for insurance and employment purposes. It does not apply to the completed BASRiS form.

However, patients have a right to request access to their clinical records, under the [Access to Health Records Act 1990<sup>29</sup>](#).

#### **5. RELEASE OF INFORMATION TO SOCIAL SECURITY SCOTLAND - WHO USES THE INFORMATION? HOW WILL THE INFORMATION BE USED? WHO IS RESPONSIBLE FOR THE FINAL DECISION?**

The information should only be released to Social Security Scotland, with the knowledge and consent of the individual or their Appointee, Legal Guardian or Power of Attorney, except where information has been withheld (see Section 7 – Harmful Information).

Social Security Scotland Case Managers are required to consider all the available evidence before making a decision about eligibility for disability assistance. The medical information you provide will be considered as part of this evidence gathering.

Decisions on disability assistance are made usually by a team in Social Security Scotland, which include non-medical/non-clinical decision-makers. One of Social Security Scotland’s Clinical Practitioners may contact you for clarification if your report is not explicit enough for a decision to be made. They will not challenge your clinical judgement in relation to the terminal nature of the disease or condition, but may need

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<sup>26</sup>[https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=7&ved=2ahUKewiqqJrssljeAhUSasAKHXB\\_D1EQFjAGegQIBRAC&url=https%3A%2F%2Fwww.bma.org.uk%2F-%2Fmedia%2Ffiles%2Fpdfs%2Fpractical%2520advice%2520at%2520work%2Fethics%2Fparentalresponsibility.pdf&usg=AOvVaw02DDWuJ2rFim\\_tVvt0nHIM](https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=7&ved=2ahUKewiqqJrssljeAhUSasAKHXB_D1EQFjAGegQIBRAC&url=https%3A%2F%2Fwww.bma.org.uk%2F-%2Fmedia%2Ffiles%2Fpdfs%2Fpractical%2520advice%2520at%2520work%2Fethics%2Fparentalresponsibility.pdf&usg=AOvVaw02DDWuJ2rFim_tVvt0nHIM)

<sup>27</sup> <https://www.rcn.org.uk/professional-development/publications/rcn-caring-for-cyp-uk-pub-009405>

<sup>28</sup> <https://www.legislation.gov.uk/ukpga/1988/28/section/1>

<sup>29</sup> <https://www.legislation.gov.uk/ukpga/1990/23/contents>

to clarify and confirm other details provided by the you (for example, in cases of illegibility).

## **6. APPEALS BY APPLICANT REGARDING DECISION MADE BY SOCIAL SECURITY SCOTLAND**

Social Security Scotland will be responsible for the decision to make an award following receipt of the BASRiS and therefore an appeal can be made against the decision of the Case Manager on the eligibility of components of the disability assistance but not against your clinical judgement. However, Social Security Scotland may contact you for further information about the content of the BASRiS form to process the application. This could be where it appears that the form has been completed by someone who is unauthorised to do so or where it is clear that the form has been completed without having regard to this guidance. Case Managers in Social Security Scotland will have access to advice from a senior medical or other clinical professionals to review the information provided in the BASRiS where needed. The intention is to audit the data collected on the various aspects of the process in this area e.g. to monitor unwarranted variation in the application of this guidance.

However, you need to be aware that the individual and/or their legal guardian may not agree with your views and may ask for a second opinion from another RMP. You should follow the usual processes for requests for a second opinion, including advice by the GMC or NMC. You should also follow the usual processes for any issues of indemnity cover and professional advice and support.

Where a patient is not deemed eligible for disability assistance under the special rules i.e. BASRiS, the patient will be able to apply for disability assistance through the standard application route, and they should be supported to do so e.g. referral to Social Security Scotland or welfare advisers.

## **7. HARMFUL INFORMATION**

Harmful information is anything that would be considered to cause serious harm to an individual's mental and/or physical health (see [GMC's Guidance on Consent](#)<sup>30</sup>), if they were to become aware of it (e.g. a diagnosis of malignancy). In practice, while addressing the needs of a patient holistically, it is understood that in most circumstances, serious harm to mental health may not be able to be separated from harm to physical health and vice versa. According to GMC guidance there is a limited exception of "serious harm" where it may be appropriate to withhold the information from the patient. "Serious harm" means more than that the patient might become upset. GMC guidance also states that, "if you delay sharing information necessary for making a decision, you should let the patient know there is more to discuss and make sure arrangements are made to share the information as soon as it's appropriate to do so. You must make a record of the information you still need to share, your reasons for not sharing it now, and when it can be shared." The information on the BASRiS form may be withheld from a patient at that time, where that is thought to be in the

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<sup>30</sup> <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent>

patient's best interests, but GMC Guidance advises that arrangements should be made to share the information as soon as it is appropriate to do so.

In the context of the BASRiS form withholding harmful information is relevant if there may be "serious harm to the physical and / or mental health of the patient or the parent/individual with legal parental responsibilities for a child". This information will then not be released to the recipient by Social Security Scotland in accordance with the [Data Protection Act 2018](#)<sup>31</sup> (see below) and the [Social Security Administration and Tribunal Membership Act 2020](#)<sup>32</sup>.

In the highly unlikely scenario that you have withheld information from your patient's legal representative/appointee, it is important that you indicate this on the BASRiS form. You are not being asked to make any additional assessment of serious mental and / or physical harm to a legal representative. It is only where, you have withheld the information on the BASRiS form from a legal representative/appointee of the patient that you need to inform Social Security Scotland of this.

This will also need to be considered where a patient or their legal representative may make a request to Social Security Scotland to access the patient's medical records.

Social Security Scotland can only withhold information from the client when the exemption in the [Data Protection Act 2018](#)<sup>33</sup> and the corresponding exemption in the [Social Security Administration and Tribunal Membership Act 2020](#)<sup>34</sup> applies. This allows information to be withheld where it is 'likely to cause serious harm to the physical and / or mental health of the data subject'. If you have withheld information it is important that this is clearly noted on the BASRiS form itself.

Where Social Security Scotland have been informed on a BASRiS form that harmful information has been withheld they will follow this up, after 3 months, by contacting the clinician and asking them to confirm whether the information continues to be withheld. If Social Security Scotland are given reason to believe harmful information is no longer withheld before the 12 weeks, they will contact the clinician earlier. This is to ensure that Social Security Scotland retains an accurate record of when harmful information is withheld.

If your reason does not fit the criteria of "serious harm to the physical and / or mental health of the patient, or parent/individual with legal parental responsibilities for a child", and they are not subject to Adults with Incapacity legislation, you will need to seek the consent of your patient before completing and sending the BASRiS form to Social Security Scotland.

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<sup>31</sup> <https://www.legislation.gov.uk/ukpga/2018/12/schedule/3>

<sup>32</sup> [Social Security Administration and Tribunal Membership \(Scotland\) Act 2020 \(legislation.gov.uk\)](#)

<sup>33</sup> <https://www.legislation.gov.uk/ukpga/2018/12/schedule/3>

<sup>34</sup> [Social Security Administration and Tribunal Membership \(Scotland\) Act 2020 \(legislation.gov.uk\)](#)

## **8. EMBARRASSING INFORMATION**

Under data protection legislation, the [Data Protection Act 2018](#)<sup>35</sup>, the fact that information would simply embarrass the author, or someone else, is not taken into account in determining whether it should be processed. Any certificates, which you provide, should not contain inappropriate personal remarks, which cannot be substantiated, and which you would not want your patient to see e.g. suspicions of exaggerating or feigning.

## **9. REHABILITATION OF OFFENDERS ACT**

To ensure compliance with the [Rehabilitation of Offenders Act 1974 \(Exclusions and Exceptions\) \(Scotland\) Order 2013 \(SI 2013/50\)](#)<sup>36</sup>, your report should not contain any reference to criminal convictions whether spent or not unless the information is directly relevant to the individual's condition. This may be relevant where, for example, a person is due to be released/liberated from prison on compassionate grounds, because of having a terminal illness.

## **10. PROCESS FOR OBTAINING BLANK BASRiS FORMS AND SENDING COMPLETED FORMS TO SOCIAL SECURITY SCOTLAND**

Please use the [Information Hub](#)<sup>37</sup> for up to date details on how to request more BASRiS forms for your organisation. To note, BASRiS forms will be numbered to prevent misuse.

The completed BASRiS form should be sent as quickly as possible to Social Security Scotland at this address:

BASRiS Form  
PO Box 27165  
Glasgow  
G4 7BR

## **11. CLAIMING FOR A FEE FOR COMPLETION OF A BASRiS FORM**

### Eligibility to claim a Fee

Independent GP contractors and private GPs, as well as GPs and RNs employed by the independent contractor and private GP practices, can submit a claim on behalf of the GP practice.

RMPs and RNs who are employed by a third sector organisation (for example a charity) can submit a claim on behalf of that organisation.

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<sup>35</sup> <http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>

<sup>36</sup> <https://www.legislation.gov.uk/ssi/2013/50/contents/made>

<sup>37</sup> <https://www.socialsecurity.gov.scot/terminal-illness>

Details of when a fee can be claimed by other medical staff are contained in the Terms and Conditions for Medical Staff in Scotland.

### Process for claiming a Fee

Please use the [Information Hub](#)<sup>38</sup> for up to date details on how to request more fee payment forms.

You should include the relevant payment details on the BASRiS fee payment form (**example in [Annex I](#)**), in order for Social Security Scotland to process your payment.

Completed fee payment forms should be posted to this address:

BASRiS Fee Payment Form  
PO Box 27165  
Glasgow  
G4 7BR

This will be processed upon receipt of the BASRiS form and BASRiS fee payment form within 30 days.

The fee for completion of the form will be: £17

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<sup>38</sup> <https://www.socialsecurity.gov.scot/guidance-resources/guidance/requesting-a-basris-form>

## **MATRIX TO SUPPORT THE CLINICAL JUDGEMENT PROCESS**

Decision of whether the individual has (having had regard to the CMO guidance), a progressive disease that can reasonably be expected to cause the individual's death, can be helped by any one or a combination of the additional criteria and indicators below. This could also take account of the carer's own experience of his/her worsening circumstances or distress, which is affecting the care of the individual.

### **Some additional criteria and indicators which may suggest that a patient is terminally ill**

Making a clinical judgement of terminal illness is an extremely complex professional clinical process, which can be an intuitive one, pulling together a range of clinical, co-morbid, social and other factors that give a whole picture of deterioration.

#### **Criteria**

Below are some of the criteria, which may be considered. It is not necessary for all the indicators to be present but several in combination would be expected. For example:

- The disease is advanced
- The disease is progressive with decreasing reversibility
- There will be deterioration of an incurable condition
- Increasing need for input of health and social care providers
- The terminal condition is not amenable to further curative treatment, or alternative treatment which is not tolerated or chosen by the patient or their legal representative
- Where death will be an inevitable consequence of the condition
- Any significant events that are likely to impact on function and life e.g. fall with significant harm
- Rapid/erratic decline, unstable
- A deteriorating condition carrying a high risk of sudden death
- Worsening or anticipated worsening of symptoms despite optimal management

#### **General indicators of decline and specific clinical indicators of terminal illness**

**A) Are there general indicators of decline – deterioration and increasing assistance for care and mobility required (it is not necessary for all the indicators to be present)?**

- Decreasing activity and function – (functional performance status declining e.g. Barthel score) limited self-care, in bed or chair for more than 50% of day, and increasing dependence in most activities of daily living
- Increasing dependence on others for unstable or deteriorating physical and mental health

- The individual's carer needs more help and support
- Significant appetite and weight loss over the last few months, or remains underweight (although some patients may gain weight – such as those with heart failure), or loss of muscle mass
- Persistent or worsening symptoms or complex symptoms despite optimal treatment of underlying condition/s
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. fall with significant harm
- No available treatment option that would lead to recovery or the person chooses not to have curative treatment for the disease causing the terminal illness

#### Functional Indicators

- Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment e.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs, etc.  
[https://www.physio-pedia.com/Barthel\\_Index](https://www.physio-pedia.com/Barthel_Index)<sup>39</sup>  
<https://www.mdcalc.com/barthel-index-activities-daily-living-adl#use-cases><sup>40</sup>
- PULSE 'screening' assessment - P (physical condition); U (upper limb function); L (lower limb function); S (sensory); E (environment).
- Australia Modified Karnofsky Performance Status Score 0-100 ADL scale.  
<https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129188.pdf><sup>41</sup>
- WHO/ECOG Performance Status 0-5 scale of activity.  
<https://ecog-acrin.org/resources/ecog-performance-status><sup>42</sup>

#### **B) Are there specific clinical indicators of terminal illness related to certain conditions?**

##### **Cancer (where decline may be rapid or more predictable)**

- Functional ability deteriorating due to progressive cancer
- Too frail for cancer treatment or treatment is only for symptom control
- Where any anti-cancer treatment is not aimed at eradicating disease

##### **Organ Failure (where decline is erratic)**

##### **Respiratory Disease**

- Severe chronic lung disease, with breathlessness at rest or on minimal effort, between exacerbations (e.g. FEV1 <30% predicted in COPD, more than 6 weeks of systemic steroids for COPD in preceding 6 months)
- Persistent hypoxia requiring long term oxygen therapy
- Has needed ventilation for respiratory failure or ventilation is contraindicated

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<sup>39</sup> [https://www.physio-pedia.com/Barthel\\_Index](https://www.physio-pedia.com/Barthel_Index)

<sup>40</sup> <https://www.mdcalc.com/barthel-index-activities-daily-living-adl#use-cases>

<sup>41</sup> <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129188.pdf>

<sup>42</sup> <https://ecog-acrin.org/resources/ecog-performance-status>

- Recurrent hospital admissions (more than 3 in last 12 months due to COPD)
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous Intensive Care Unit/Non Invasive Ventilation (ITU/NIV) resistant organisms

### ***Heart/Vascular Disease***

- Heart failure or extensive untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal exertion
- Severe inoperable peripheral artery disease
- Repeated hospital admissions with heart failure symptoms

### ***Kidney Disease***

- Stage 4 or 5 Chronic Kidney Disease (CKD) – eGFR<30ml/min, with deteriorating health
- Kidney failure complicating other life limiting conditions e.g. symptoms of nausea and vomiting, anorexia, pruritus, reduced functional status and intractable fluid overload
- Stopping or not starting dialysis, even following transplant failure

### ***Liver Disease***

- Cirrhosis with one or more complications in the past year – diuretic resistant ascites; hepatic encephalopathy; hepatorenal syndrome bacterial peritonitis; recurrent variceal bleeds
- Liver transplant is not possible.

### **General Neurological Diseases**

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Speech problems with increasing difficulties in communicating
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis
- Breathlessness or respiratory failure
- Labile blood pressure
- Speech problems with increasing difficulty in communications (progressive dysphasia).

### **Specific Neurological Diseases**

#### ***Parkinson's Disease***

- Reduced independence, needs increasing help with activities of daily living
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Increased cognitive difficulties/significant cognitive deterioration
- Similar pattern to frailty with one or more co-morbid diseases/conditions - see "Frailty with one or more co-morbid diseases/conditions" section below.

#### ***Motor Neurone Disease***

- Marked rapid decline in physical status
- Difficulty in swallowing, first episode of aspiration pneumonia
- Low vital capacity (below 70% of predicted using standard spirometry)
- Weight Loss

- Increased cognitive difficulties
- Significant complex symptoms and medical complications
- Communication difficulties.

### ***Multiple Sclerosis***

- Significant complex symptoms and medical complications
- Dysphagia, poor nutritional status
- Communication difficulties e.g. Dysarthria, fatigue
- Cognitive impairment e.g. dementia – see “Dementia” section below.

### **Stroke**

- Dense paralysis
- Minimal conscious state
- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis,
- Breathlessness or respiratory failure
- Speech problems with increasing difficulty with communication (progressive dysphasia)
- Frailty with stroke and post stroke dementia – see “Dementia” section below.

### **Frailty with one or more co-morbid diseases/conditions and Advanced Dementia (where there is gradual decline)**

Dementia - There are many underlying conditions, which may lead to degrees of dementia, and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk, dress or eat without assistance,
- Eating and drinking less, difficulty in swallowing
- Weight loss
- Urinary and faecal incontinence
- Not able to communicate by speaking i.e. no meaningful conversation, little social interaction
- Frequent falls, with or without fractures
- Recurrent febrile episodes or infections, aspiration pneumonia
- Severe pressure sores e.g. ulcers with deeper involvement of underlying tissue with more extensive destruction, such as extending into the muscle, tendon or even bone.

## **TOOLS TO SUPPORT CLINICAL JUDGEMENT**

### **University of Edinburgh Supportive and Palliative Care Indicators Tool (SPICT™)**



SPICT April2017.pdf

<https://www.spict.org.uk/><sup>43</sup>

### **iHub Palliative Care Identification Tools Comparator**



palliative-care-ident  
ification-tools-comp

<https://ihub.scot/media/2079/palliative-care-identification-tools-comparator.pdf><sup>44</sup>

### **Outcome Assessment and Complexity Collaborative – Summary of Suite of Measures**

### **Healthcare Improvement Scotland's Scottish Anticipatory Care Programme**

<https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>

### **Effective Communication for Healthcare – Anticipatory Care Planning in Scotland**

<http://www.ec4h.org.uk/resources/anticipatory-care-planning-in-scotland/>

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<sup>43</sup> <https://www.spict.org.uk/>

<sup>44</sup> <https://ihub.scot/media/2079/palliative-care-identification-tools-comparator.pdf>

**WORKED EXAMPLES (ADULTS, BABIES, CHILDREN AND YOUNG PEOPLE)****Adult Examples****Colon cancer (break-down in relationship with GP) – Simon**

Simon is 45. He was diagnosed with colon cancer and liver metastasis, and is undergoing palliative chemotherapy. He was not issued a BASRiS form at his initial referral.

Simon had been seeing his GP for up to two years with symptoms consistent with his diagnosis. Simon's view is that the GP failed to send him for tests until recently, leading to a delay in the diagnosis. Simon does not want to approach his GP due to a breakdown in their relationship.

Simon has a number of options in this situation. He is still able to make an application to Social Security Scotland for disability assistance when Adult Disability Payment has commenced in Scotland, indicating that he has a terminal illness and explaining his declining condition. Social Security Scotland could seek to obtain a BASRiS form on his behalf by contacting the healthcare practitioner Simon names on the application form and enquiring whether a BASRiS is appropriate.

Simon could approach another GP in the practice, who has access to his clinical records, as well as reports from other professionals involved in his care. He could also approach the specialist doctor involved in his care. Either doctor would be able to sign the BASRiS form.

Simon would also be able to make a complaint through the NHS complaints procedure if he wished to do so. This would not be a matter for Social Security Scotland.

**COPD - Marilyn**

Marilyn is 58. she has severe COPD and graded as Medical Research Council (MRC) grade 4 (Stops for breath after walking about 100 metres or after a few minutes on level ground.)

She can walk up to 500 metres with frequent pauses for breath, using a wheeled trolley, continues to smoke, experiences infective exacerbations perhaps 4 times per year, and has required one admission for this in the last year.

She would be graded as Group D in the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria (Group D: high risk ( $\geq 2$  exacerbations per year, or one or more requiring hospitalisation) and more symptoms Modified Medical Research Council dyspnoea scale (mMRC) $\geq 2$  or COPD Assessment Test (CAT) $\geq 10$ ).

Marilyn will almost certainly die within the next few years, but currently there are no signs of rapid decline and completion of a BASRiS form at this stage would be inappropriate.

### **COPD (choosing not to take clinical advice) – Archie**

Archie is 52 and has COPD. He has refused to comply with medical advice about his lifestyle and does not take his prescribed medication. If this continues, Archie's GP expects that he will die within a year.

It is Archie's human right to choose his course of treatment (including refusing treatment), and if his GP's diagnosis is that Archie's condition presents an imminent threat to his life without management, then the GP should complete a BASRiS form for Adult Disability Payment once it has commenced in Scotland.

### **Dementia, frailty with one or more co-morbid diseases/conditions, and recurrent pneumonia – Moira**

Moira is an 87 year old who lives with her husband. Over the last few years, she has been developing symptoms of dementia and has become increasingly frail. Owing to a desire to maintain independence, and a fear that contact with health and social care would result in Moira "being put into a home", they have not sought help until recently, when Moira developed recurrent pneumonia. It is felt that this was as a result of swallowing problems caused by her dementia.

On its own, Moira's dementia would be unlikely to lead a clinician to diagnose her as terminally ill for the purposes of access to disability assistance. However, the multimorbid combination of dementia with recurrent pneumonia may lead a clinician to judge Moira's condition as terminal, and to complete a BASRiS form in relation to a claim for Pension Age Disability Payment (which only has a care component), once that benefit is being delivered by Social Security Scotland.

### **Duchenne Muscular Dystrophy - John**

John is a 24 year old man with Duchenne Muscular Dystrophy. In general, he has done better than his elder brother who died 5 years ago from complications of the same condition. This discrepancy between John and his brother is likely to be due to a number of medical interventions, which John has undergone, including: the orthopaedic insertion of rods in his back, the introduction of feeding by gastrostomy, robust management of his underlying cardiac condition, and the use of overnight non-invasive ventilation. In recent months, John has required the use of his non-invasive ventilator for longer periods throughout the day and night. So far, he and his parents have not wanted to discuss detailed planning for the future, and have preferred not to engage with statutory services about Adult Disability Payment.

John develops a significant chest infection, and after a 2 week period in hospital is discharged home, where it is clear that both parents will now both need to stay at home to help look after him. After much discussion with their Respiratory Physician and their District Nurse, they approach their GP to assist them with a claim for Adult Disability Payment.

In this case, the GP must use their clinical judgement consulting the Clinical Assessment of Terminal Illness section – as well as evidence gathered from John's specialist, nurse, and family – to establish whether John's condition is likely to lead to his death. If John's condition is judged to be terminal, then the GP should complete a

BASRiS form in relation to Adult Disability Payment. This would fast-track John to the highest rates of both care and mobility for the benefit. However, if John's condition has worsened, *but* has since stabilised and he does not require expedited access to benefits, the family should apply for Adult Disability Payment through the standard route.

In either case, the GP should also sign-post John's parents to Carer's Allowance (a devolved benefit currently, being delivered by DWP), and the Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland), since one of them may be eligible.

### **Elderly with several conditions - Chen**

Chen is 84. She has a longstanding diagnosis of Alzheimers disease and has previously been thought to be mildly affected, managing to live alone with a minimal package of care. She was unfortunately hospitalised 3 months ago with an intracerebral haemorrhage, which has left her with significant left-sided weakness. Shortly after hospital discharge, she developed worsening confusion and agitation. She was again admitted to hospital and treated for urinary tract infection. Since subsequent discharge 2 months ago, she remains significantly confused, her mobility has deteriorated substantially, and she is requiring maximal package of care at home.

Chen's condition is such that she would be eligible for the Pension Age Disability Payment under the special rules, and a BASRiS form can be completed by her GP or hospital doctor.

### **Glioblastoma (appointee) - Abdul**

Abdul is a 56 year old man who was diagnosed with Glioblastoma in September 2016. Because of diminished mental capacity as a result of his condition, Abdul had an appointee until recently. However, following a breakdown in their relationship, he has appointed MacMillan's Welfare Rights Service as responsible for his benefits until his death.

Abdul has an existing DS 1500 in relation to Universal Credit (UC) claim and for his Personal Independence Payment (PIP) with Department for Work and Pensions (DWP). Abdul's GP need not take any action. The DS 1500 will remain in place for his UC claim. The DS 1500 will be automatically accepted in place of a BASRiS form, when Adult Disability Payment is implemented in Scotland and Abdul will be transferred to the Scottish system in time. If approached by the MacMillan Welfare Rights Service, in their capacity as Abdul's appointee, this should be explained to them.

### **Heart Failure - Harry**

Harry is 56, and was diagnosed with Heart Failure recently. He gave up work quite suddenly as his fatigue and breathlessness were triggered by even minor physical activity and he found it difficult to keep up with the physical demands of his job.

Harry recently had an admission to hospital because of his heart failure. Even though his prognosis is unpredictable, Harry has significant supportive care needs. Harry's GP was reluctant to sign a DS 1500 because; she could not predict that he was in his

last 6 months of life. People with Heart Failure often experience periods of decline and recovery, which can make this prediction particularly difficult.

Under BASRiS rules, Harry's GP has the discretion to use her clinical judgement about his deterioration in being able to cope with activities of daily living, his recent hospital admission and the persistence of worrying symptoms despite optimal treatment. If Harry is deemed to be terminally ill, his GP should fill in a BASRiS form for Adult Disability Payment when this has commenced in Scotland. This would entitle Harry to the highest rates for both mobility and care.

Harry may also be eligible for Employment Support Allowance, however, if he wished to access this benefit under special rules for terminal illness, he would need to meet the DWP's terminal illness definition, since the benefit is currently reserved to the UK Government. However, he is still able to apply through the standard route. Since the benefit is currently reserved to the UK Government he would need to contact DWP to apply for this benefit.

### **Cancer of the intestine (migration from DS 1500) - Gary**

Gary is 67. He is currently not in receipt of any disability benefits. He has a diagnosis of cancer of the intestine. Following unsuccessful surgery, the cancer spread throughout his abdomen and lungs. Gary is the main carer for his wife (66), who has a rare heart condition that leaves her very breathless, dizzy and fatigued. His wife currently receives the Attendance Allowance (which only has a care component).

Gary's consultant established that he was "terminally ill" as per the DWP definition, and completed form DS1500 on his behalf. Following this Gary was fast-tracked onto Attendance Allowance (which only has a care component), at the higher rate.

When BASRiS was introduced, Gary presented at his GP requesting that he be transferred to the Scottish system, to take advantage of the additional rules under BASRiS. Since he already has a DS1500, Gary will be transferred to the Scottish system in time, and the GP will not need to do anything further. If he is not already claiming Carer's Allowance (a devolved benefit currently being delivered by DWP) and the Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland), the GP may also flag his potential eligibility for this benefit in relation to the care he provides to his wife.

### **Terminal lung cancer (but patient currently feels well) - Frank**

Frank is 55. He was diagnosed with lung cancer 9 months ago. Frank's very direct-talking oncologist has told him that his illness is advanced and progressive. However, at the moment, Frank feels surprisingly well. Aside from a bit of a cough (which is not really any worse than the one he usually has), he is free of symptoms. He can do pretty much everything he wants to do – get out and about, look after himself and still take care of his grandchildren.

Frank's oncologist has been clear that his condition is deteriorating, and is likely to result in his death in the near future. Furthermore, his condition may deteriorate suddenly, and without warning. Frank would be eligible for Adult Disability Payment (when implemented in Scotland), under BASRiS based on Frank's oncologist's assessment.

Although Frank currently feels well, it is very likely that his care needs will increase quickly. It is advisable that Frank applies for Adult Disability Payment under BASRiS at his earliest convenience.

### **Motor Neurone Disease (rapid decline in condition) - Derek**

Derek is 54 years old and, 3 months ago, was diagnosed with Motor Neurone Disease (MND), a rapidly progressing terminal illness. Already Derek has lost much of the use of his hands and is walking with a limp. It is anticipated that he will soon need to use a wheelchair. He could request a BASRiS form or the RMP may decide to consider completing a BASRiS form for him.

Consulting the Clinical Assessment of Terminal Illness section of the Guidance (currently Section 7), and speaking to Derek's MND clinical specialist, his GP sees that, with a diagnosis of MND, Derek meets or surpasses the indicators listed.

His GP decides that, clearly, Derek qualifies for a BASRiS and needs to be fast-tracked for his benefits. Derek's GP promptly completes the BASRiS form and sends it to Social Security Scotland. This enables Derek to receive Adult Disability Payment, at the highest rates, and may allow his partner to access Carer's Allowance (a devolved benefit currently being delivered by DWP) and the Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland), much quicker than if he had to apply following the normal route.

### **Multi-morbidity and frailty - Brenda**

Brenda is 103 and lives at home, supported by her daughter and great neighbours. She has diagnoses of dementia (early stage), arthritis, macular degeneration, diabetes and is generally very frail, and getting less mobile and able to look after herself. She has periodic chest infections, which can get quite bad – sometimes these are managed at home, but a couple of times in the last 5 years she has been admitted to hospital.

BASRiS may be appropriate in this case, if the clinical judgement after consulting the Clinical Assessment of Terminal Illness section is that Brenda has severe frailty. Were Brenda to apply for the Pension Age Disability Payment when it is implemented in Scotland, (which only has a care component), and qualify under BASRiS, her claim would be fast-tracked. Her award would be at the higher rate, with no review period. Brenda's daughter or one of her neighbours may be eligible for Carer's Allowance (a devolved benefit currently being delivered by DWP) and the Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland), if Brenda is awarded the Pension Age Disability Payment.

### **Unknown neurological disorder - Kate**

Kate is 47. She is an ex healthcare worker who lives alone, with supportive son and daughter nearby. There is a background of COPD with longstanding heavy smoking. She has been under neurology review for a year with steadily progressive imbalance and speech problems, which have been deteriorating over the year. She is now using a wheelchair and able to walk only a few steps. Despite detailed investigation, no specific cause has been found. Attempted treatments have not helped. Her consultant believes she may have a cancer-related (paraneoplastic) disorder related to an

unidentified tumour, or perhaps a degenerative disorder. She cannot suggest any further treatments. Her son and daughter are increasingly struggling to support her because of poor mobility and shortness of breath. She was recently hospitalised with pneumonia.

If it is Kate's consultant's clinical judgement that Kate is likely to die from her condition, then she should fill out a BASRiS form, to allow Kate to access Adult Disability Payment under special rules. Kate's son or daughter may be eligible for Carer's Allowance (a devolved benefit currently being delivered by DWP) and Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland). It is not necessary for the consultant to be certain, nor is it necessary for the condition to have a confirmed named diagnosis if Kate displays indicators set out in the CMO guidance.

### **Old age - Ina**

Ina is a 92 year old lady who lives alone in a retirement flat. She has been active and independent since an aortic valve replacement ten years ago. She receives blood thinning for her metallic heart valve and treatment for high blood pressure, previous angina, and an underactive thyroid. She was managing 9 holes of golf a week until the end of last summer, but has given this up for fear of slowing her friends down. Since then, visitors have commented to her that she seems to be losing weight. After a discussion with her GP, she has decided against any investigations regarding this, but her weight loss continues and she has recently started to rely on her neighbours more and more.

Ina's clinician would need to establish whether she was likely to die from one, or a combination, of these diagnosed or undiagnosed conditions. If it is the clinical judgement of the GP, after consulting the Clinical Assessment of Terminal Illness section, that Ina's condition/s are terminal, and she is likely to die soon, they should complete a BASRiS form in relation to a claim for the Pension Age Disability Payment, (which only has a care component), when it is implemented in Scotland. However, if it is the clinician's judgement that Ina's condition is consistent with, and typical of old age alone, this would not be grounds alone for completion of the BASRiS, and Ina should be encouraged to make an application for the Pension Age Disability Payment (which only has a care component), by the standard route.

### **Reduced mental and physical capability following a stroke (existing DS 1500) – Jennifer**

Jennifer is 52. Jennifer has reduced mental and physical capability following a stroke, and currently receives the highest rates of Adult Disability Payment, for both care and mobility. Jennifer presents at her GP with symptoms including headaches and vomiting. After a specialist appointment, Jennifer's GP informs her that she has advanced Glioblastoma. Exercising clinical judgement, Jennifer's GP deems her condition terminal under the Clinical Assessment of Terminal Illness section.

Although Jennifer is already on the highest rate of the Adult Disability Payment the additional rules under BASRiS e.g. the lack of reassessment period, make it

worthwhile transferring to the terminal illness rules. This should be done through the BASRiS form, as with any other person who is terminally ill.

### **Children and Young People's examples**

#### **Rare brain tumour - Fiona**

Fiona is a 6 year old girl with a rare brain tumour, which is very unresponsive to chemotherapy, radiotherapy or surgery. She is being considered for phase one and 2 trials, but none fits with her condition. She is being maintained on low doses of dexamethasone with boost of doses, and with oral etoposide, which is a form of palliative chemotherapy. Fiona has spent a number of months as an inpatient in the local children's ward.

She has twin sisters who are 2 years old, and her Mum has not returned to work since their birth, which was just after Fiona's initial diagnosis. Both of Fiona's parents are still hopeful that she can improve and are in touch with multiple specialist groups across the world, but at present her father is about to be made redundant because of a re-organisation at his work.

Using clinical judgement consulting the Clinical Assessment of Terminal Illness section – and having gathered evidence from specialist nurses who have worked with Fiona on the children's ward – the medical practitioner should establish whether Fiona is likely to die from her condition. Following this diagnostic process, the medical practitioner has a number of options.

1. If Fiona's condition is judged to be terminal:

a) Fiona's parents are hopeful, but this may not reflect the seriousness of Fiona's condition, then the medical practitioner may fill out a BASRiS form (in relation to a claim for Child Disability Payment without informing the parents of the terminal nature of Fiona's condition (if this information is deemed to be harmful); or

b) The medical practitioner may wish to have the difficult conversation with the parents, to inform them of the nature of Fiona's condition, and complete a BASRiS form with their full knowledge and consent.

Both options – 1a and 1b – would fast-track Fiona's claim, and automatically entitle her to the highest rates for both care and mobility.

2. If it is established that Fiona is likely to recover, the medical practitioner should still signpost the family toward Child Disability Payment, when it is implemented in Scotland. They would simply apply through the standard route, without recourse to the special rules.

In all cases above, the medical practitioner should also signpost Fiona's parents to Carer's Allowance (a devolved benefit currently being delivered by DWP) and the Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland), since one of them may be eligible.

## **Inherited condition which is terminal – Rizwan**

Rizwan is a 3 month old baby who was born by Caesarean Section at 32 weeks gestation, following the antenatal diagnosis of an inherited condition. It was not clear if he would survive beyond the first few days, and at this point is being considered for transfer to a high dependency unit. Rizwan may require a tracheostomy to maintain his airway in the long term, but he remains at considerable risk of a deterioration, which could lead to death in the next few years. Six years ago, Rizwan's parents had a little girl who sadly died from a variant of the same condition.

Rizwan's parents are unable to work, and they have two other children aged 4 and 7.

Rizwan's clinician may use their clinical judgement to establish whether Rizwan is likely to die of this condition. If Rizwan's clinician, consulting the Clinical Assessment of Terminal Illness section, judges that he is terminally ill, she should fill out the BASRiS form in relation to a claim for the Child Disability Payment, when it is implemented in Scotland. This would fast-track Rizwan's claim, and automatically entitle him to the highest rate of care. The clinician should also signpost Rizwan's parents to Carer's Allowance (a devolved benefit currently being delivered by DWP) and the Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland), since one of them may be eligible.



**Benefits Assessment under Special Rules in Scotland (BASRiS) Form for Terminal Illness**

(Applies to Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment) **Please complete promptly**

**Patient**

1 Surname

2 Other names

3 Date of birth

4 CHI number

5 Address

6 Postcode

**The Condition:**

**Part 1**

1 What is the diagnosis

*Example*

2 Other relevant diagnosis

*The Condition Continued:*

3 Is the patient aware of their condition    Yes     No

4 Is the patient aware of their prognosis    Yes     No

If the patient is an adult and the answer is no to either 3 or 4, please provide the name, contact details of their legal representative (address, email, telephone) and relationship to the patient (guardian/appointee);

**OR**

If the patient is a child, please provide below, the name, contact details of their parent or legal representative and their relationship to the child (parent/guardian/kinship carer/appointee)

Name

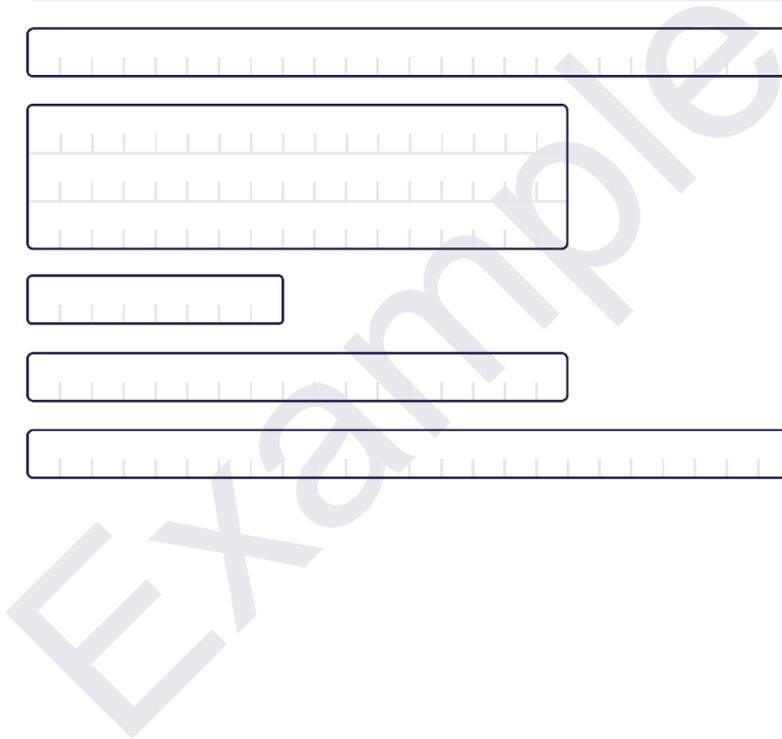
Relationship

Address

Postcode

Phone number

Email if available



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## Part 2 - Clinical Indicators which support your clinical judgement

Please give details of the three Indicators which support your clinical judgement. In filling in this section, you should provide details related to the indicators set out in section 7, also with particular reference to bullet points five to eight in section 8 (highlighted in bold), of the accompanying guidance. The indicators can be used for conditions which go beyond cancer to include other areas, whether they are single or multiple conditions, such as organ failure (respiratory disease, heart/vascular disease, kidney disease, liver disease); neurological diseases (Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis); Stroke; Frailty with one or more co-morbid diseases/conditions; Dementia; and rare conditions or diseases. This list is not exhaustive. In addition, individuals' eligibility for BASRiS also could be established based on a combination of diseases with conditions, and your clinical judgement about the requirement for expedited access to disability assistance.

If it is not possible to give a definitive diagnosis, please apply the indicators as described in the previous paragraph, and give details of condition (e.g. a neurological condition, multisystem disorder), relevant current treatment, its purpose and response e.g. palliative care, decreasing reversibility, deteriorating symptoms, increasing input of health and social care providers.

Example

Is there any other intervention or treatment planned which may significantly alter the progression of the condition?

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## Declaration

I have been professionally involved in the diagnosis and/or care of the patient and had access to the relevant clinical records to provide this report to the best of my knowledge and belief.

I believe that this patient is terminally ill according to the indicators laid out in the "Clinical Assessment of Terminal Illness" (Section 7) of the CMO GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND (BASRiS) FORM FOR TERMINAL ILLNESS.

I have sought and obtained valid consent from the patient and or their legal representative to share the information included in this form with Social Security Scotland.

This has been noted in the patient's clinical records.

Yes  No

### OR

I have not obtained consent because disclosure of information included in this form would be likely to cause serious mental and / or physical harm to the patient or a child's parent/individual with legal parental responsibilities, if they were to become aware of it. This has been noted in the patient's clinical records.

Yes  No

I have not disclosed the information included in this form to the patient's legal representative.

Yes  No

### This is because:

It would be likely to cause serious mental and / or physical harm to the patient's legal representative.

Yes  No

### OR

For any other reason (for example I have not spoken to them).

Yes  No

This has been noted in the patient's clinical records.

Yes  No

I am a Registered Medical Practitioner or I am a Registered Nurse.

1 Name

2 GMC No

3 NMC No

4 Work Phone number

5 Work Email Address

6 Work Address

7 Postcode

8 Signature

9 Date

Please post the completed form to: **BASRiS PO Box 27165 GLASGOW G4 7BR**

COMMS/BASRiS Medical Form/V2/May 2021

## CURRENT BENEFITS DEVOLVED TO SCOTLAND - Social Security in Scotland by Recipient Group

**Key** Benefits covered by this guidance are marked with \*

Devolved benefits are in bold type

Benefits for people out of work	Benefits for elderly people	Benefits for people who are ill or disabled	Benefits for families with children	Benefits for people on low incomes	Other
<ul style="list-style-type: none"> <li>Income Support</li> <li>In Work Credit &amp; Return to Work Credit</li> <li>Job Grant</li> <li>Jobseekers Allowance</li> </ul>	<ul style="list-style-type: none"> <li><b>Winter Fuel Payments</b></li> <li>Financial Assistance Scheme</li> <li>Pension Credit</li> <li>State Pension</li> <li>State Pension Transfers</li> <li>TV Licences</li> </ul>	<ul style="list-style-type: none"> <li><b>Attendance Allowance *</b></li> <li><b>Carer's Allowance</b></li> <li><b>Carer's Allowance Supplement</b></li> <li><b>Disability Living Allowance *</b></li> <li><b>Personal Independence Payment *</b></li> <li><b>Severe Disablement Allowance</b></li> <li>Employment &amp; Support Allowance</li> <li>Incapacity Benefit</li> <li>Industrial Injuries</li> <li>Specialised Vehicles fund</li> <li>Statutory Sick Pay</li> </ul>	<ul style="list-style-type: none"> <li>Child Benefit</li> <li>Child Tax Credit</li> <li>Guardians Allowance</li> <li>Maternity Allowance</li> <li>Statutory Maternity Pay</li> </ul>	<ul style="list-style-type: none"> <li><b>Discretionary Housing Payments</b></li> <li><b>Scottish Welfare Fund</b></li> <li><b>Regulated Social Fund (Sure Start Maternity Grant, Cold Weather Payments and Funeral payments)</b></li> <li>New Deal &amp; Employment Programme Allowances</li> <li>New Enterprise Allowance</li> <li>Working Tax Credit</li> <li>Housing Benefit</li> </ul>	<ul style="list-style-type: none"> <li>Universal Credit, inc. <b>UC Scottish Choices</b></li> <li>Bereavement benefits</li> <li>Christmas bonus</li> <li>Other small benefits such as child trust fund etc.</li> </ul>

Devolved Benefits that are Affected or Not Affected by BASRiS		
	Benefit	Primary benefit purpose
Disability Benefits Requiring BASRiS when their Scottish replacements are in place in Scotland	<a href="#">Attendance allowance</a> <sup>45</sup>	To help with personal care for individuals aged 65 or over with a physical or mental disability.
	<a href="#">Disability Living Allowance</a> <sup>46</sup>	Help if your disability or health condition means one or both of the following are true: You need help looking after yourself, or you have walking difficulties. DLA is closed to new working age claimants and being replaced by Personal Independence Payment (PIP).
	<a href="#">Personal Independence Payment</a> <sup>47</sup>	Helps with some of the extra costs caused by long term ill health or disability for individuals aged 16 to 64. Replacement for DLA for working age individuals.
Devolved Benefits a patient or carer may be entitled to.	<a href="#">Carer's Allowance</a> <sup>48</sup>	To help an individual look after someone with substantial caring needs. To be eligible the individual must be 16 or over and spend at least 35 hours a week caring for them.
	<a href="#">Carer's Allowance Supplement</a> <sup>49</sup>	An extra payment to help carers in Scotland who get Carer's Allowance
	<a href="#">UC Scottish Choices</a> <sup>50</sup>	<a href="#">UC Scottish choices</a> <sup>51</sup> give recipients of Universal Credit (UC) in Scotland a choice to have their UC award paid either monthly or twice monthly, and have the housing costs in their award of UC paid direct to their landlord.

Details of *all* devolved benefits can be found [here](#)

<sup>45</sup> <https://www.gov.uk/attendance-allowance>

<sup>46</sup> <https://www.gov.uk/browse/disabilities/benefits>

<sup>47</sup> <https://www.gov.uk/pip>

<sup>48</sup> <https://www.gov.uk/carers-allowance>

<sup>49</sup> <https://www.gov.scot/policies/social-security/benefits-for-carers/>

<sup>50</sup> [Social security: Universal Credit \(Scottish choices\) - gov.scot \(www.gov.scot\)](#)

<sup>51</sup> [Social security: Universal Credit \(Scottish choices\) - gov.scot \(www.gov.scot\)](#)

DS 1500

Doctor's Report for Disability Living Allowance, Attendance Allowance or Incapacity Benefit to accompany your patient's claim under Special Rules	
<b>THIS IS NOT A CLAIM FORM</b>	
Patient's copy	
Surname	Address
Other names	
Date of birth	
<b>Part 1 - Condition</b>	
What is the diagnosis?	Other relevant diagnoses?
Date of diagnosis?	
Is the patient aware of their condition and/or prognosis? YES <input type="checkbox"/> NO <input type="checkbox"/>	
If not, please tell us the address of their representative	
<b>Part 2 - Clinical Features</b> which indicate a severe progressive condition. (For example: rate of progression, recurrence, staging, tumour markers, CD4 count and viral load, bulbar involvement, respiratory and/or heart failure etc.)	
<b>Part 3 - Treatment</b>	
Please give details of relevant past or current treatment with dates including response (if not curative please state)	Is any other intervention or treatment planned which may significantly alter progression of the condition?
<b>Declaration:</b> the person named above is my patient. This is a full report of their condition and treatment. I have read and understand the notes on the completion of this form and I am satisfied that the form is appropriate. I am the patient's:	
<input type="checkbox"/> Registered General Practitioner	Address or FHSA stamp
<input type="checkbox"/> Hospital or hospice consultant	
<input type="checkbox"/> _____	
Signature	
Your name	
Phone number	Date
	<b>DS1500</b>

## **THE SCOTTISH SOCIAL SECURITY PRINCIPLES**

### **The Scottish social security principles are:**

- social security is an investment in the people of Scotland
- social security is itself a human right and essential to the realisation of other human rights
- the delivery of social security is a public service
- respect for the dignity of individuals is to be at the heart of the Scottish social security system
- the Scottish social security system is intended to contribute to reducing poverty in Scotland
- the Scottish social security system is should be designed with the people of Scotland on the basis of evidence
- opportunities should be sought to continuously improve the Scottish social security system in ways which -
  - put the needs of those who require assistance first, and
  - advance equality and non-discrimination
- the Scottish social security system should be efficient and deliver value for money.

### **Effect of the principles**

The Scottish social security principles are to be reflected in the Scottish social security charter

The Scottish Commission on Social Security is to have regard to the principles in preparing reports on proposals for legislation

A court or tribunal in civil or criminal proceedings may take the Scottish social security principles into account when determining any question arising in the proceedings to which the principles are relevant.

Breach of the principles does not itself give rise to grounds for any legal action.

### **Link to the Social Security (Scotland) Act 2018:**

[http://www.legislation.gov.uk/asp/2018/9/pdfs/asp\\_20180009\\_en.pdf](http://www.legislation.gov.uk/asp/2018/9/pdfs/asp_20180009_en.pdf)<sup>52</sup>

### **Link to Schedule 5 – Disability Assistance Regulations (introduced by Section 31 of the Act):**

<http://www.legislation.gov.uk/asp/2018/9/schedule/5/enacted><sup>53</sup>

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<sup>52</sup> [http://www.legislation.gov.uk/asp/2018/9/pdfs/asp\\_20180009\\_en.pdf](http://www.legislation.gov.uk/asp/2018/9/pdfs/asp_20180009_en.pdf)

<sup>53</sup> [Social Security \(Scotland\) Act 2018 \(legislation.gov.uk\)](http://www.legislation.gov.uk/asp/2018/9/schedule/5/enacted)

## **Implications for Disability Benefits under Special Rules – Terminal illness**

If eligible for special rules, the patient's application for benefits assistance will be processed differently to standard benefit applications. This means that:

- There is no qualifying period. An individual is not required to have the condition for any length of time before they are eligible under special rules.
- Once verification has been given that the person is considered to have a terminal illness, for the purpose of entitlement to disability assistance, there is no requirement for an individual to undergo any further assessment to establish that a person has a terminal illness.
- Awards will be calculated, at the latest, from the date of application by the patient.
- Patients who qualify under special rules will be automatically entitled to the highest rate of the component part(s) of whichever benefit they are entitled to e.g. the current Attendance Allowance does not have a "mobility" component.

It may also enable the patient's carer(s) to access Carer's Allowance quicker, as this is a 'passported' benefit, dependent on the patient receiving one of the disability benefits.

The information in this guidance will also be relevant to other practitioners who advise patients regarding benefits assistance e.g. Citizens Advice Scotland.

## FURTHER SUPPORTING INFORMATION

### **Information Leaflets**

Two information leaflets have been developed. These are intended to highlight the recent changes and new processes in Scotland for accessing disability assistance for people who are terminally ill.

Please use this link to access the [leaflet for clinicians](#)<sup>54</sup>.

Please use this link to access the [leaflet for people who are terminally ill and those who support them](#)<sup>55</sup>.

### **Frequently Asked Questions**

To further support clinicians in using this guidance and supporting patients who are terminally ill a list of frequently asked questions has been developed. Please use this link to access the [FAQs](#)<sup>56</sup>.

### **Information Hub**

All related information to support clinicians using the new terminal illness definition is being published in one place on Social Security Scotland's website. This includes:

- CMO guidance
- FAQs
- CMO / CNO letter to all RMPs and RNs
- Information leaflets (for clinicians and for people who are terminally ill and those who support them)
- Clear information regarding launch dates of each new disability benefit and clear guidance regarding when the new terminal illness definition is live for each age group
- Clear guidance on whether a DS1500 form or a BASRiS form is required
- Information on where BASRiS forms can be obtained and where they need to be sent
- Information on Social Security Scotland's 'Clinical Helpline' which has been established to support clinicians

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<sup>54</sup> <https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-factsheet-for-clinicians>

<sup>55</sup> <https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-leaflet-for-patients>

<sup>56</sup> <https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-frequently-asked-questions>

Please use this link to access the [Information Hub](#)<sup>57</sup>.

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<sup>57</sup> <https://www.socialsecurity.gov.scot/terminal-illness>

## BASRiS FEE PAYMENT FORM

### For General Practitioners and RMPs and RNs in GP Practices and in third sector organisations not employed by Health Boards

This is an example of the Fee Payment Form which can be used to claim a fee for a submitted BASRiS form. Please complete all the boxes on this form to assist payment. Payment can only be made if the completed Fee Payment Form (and the related BASRiS form) is received by Social Security Scotland.



Social Security Scotland  
Tearainteachd Shòisealta Alba

**Payment Form**  
Benefits Assessment Under Special Rules in Scotland  
(BASRiS)

#### BASRiS Payment Section:

Eligibility to claim a fee for completing the BASRiS and the fee amount is contained within the 'Guidance for Doctors and Nurses Completing Benefits Assessment Under Special Rules for Scotland Advice from the Chief Medical Officer'. If you are eligible to claim the fee, please complete the information below and send this form for payment to: **BASRiS Payment, PO Box 27165, Glasgow G4 7BR**

Confirm that you have checked and are eligible to claim the fee

1 GP Practice or Organisation or Name

Address

Town/City

Postcode

Country

Email address

2 Are you registered for VAT Yes  No

VAT reference Number

Fee Amount

3 Please enter details below

Name of Bank or Building Society

Account Name

Sort code

Account number

Roll Number (building society only)



4 To help us process the payment, please complete the following:

A Patient CHI Number

b Patients Surname

c Patients First Name

d Patients Date of birth

7 Date of Consultation

Example