

POLICY POSITION PAPER

DISABILITY ASSISTANCE: TERMINAL ILLNESS DEFINITION AND RULES

Introduction

This paper is one of a series of papers providing an update on our position on various matters relating to the development of Disability Assistance and Social Security benefits. The purpose of this paper is to set out the Scottish Government's position and progress in developing a new definition of terminal illness. The new definition will be used to determine whether an individual is eligible to receive Disability Assistance because they are terminally ill.

Background

The Scottish Government included provision in the Social Security (Scotland) Act 2018 to introduce a new definition of terminal illness that differs from the current UK Government definition. Therefore when making Disability Assistance Regulations under the Act the definition 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 a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death.

This differs from the current UK DWP Social Security legislation where a person is deemed terminally ill if: *'they suffer from "a progressive disease and their death as a consequence of that disease can be reasonably expected within 6 months'*.

Support for people who are terminally ill is a complex, sensitive and difficult issue. The Scottish Government is aware that behind the decisions that we make are thousands of people who we must put front and centre of our decisions and actions. Following extensive consultation with medical professionals and wider stakeholders we were told that the same condition may have different impacts on individuals, sometimes resulting in significant needs due to deteriorating function. In these instances, individuals who are not likely to die within 6 months may still require support much earlier than the normal application route for disability benefits currently allows. The new approach to terminal illness in Scotland will allow medical professionals to use their clinical judgement on a case by case basis to ensure that those individuals who need support, receive it quickly.

The new definition will be introduced to ensure that the sensitive and difficult conversations between an individual and their clinician that are required in these difficult circumstances, are held when medically necessary, to allow for optimal focus on the patient. It sets no arbitrary timeframe and it recognises that it is the skill and expertise of the registered medical practitioner that is needed to determine a terminal diagnosis.

Chief Medical Officer's (CMO) Guidance

To support that critical decision making, the CMO, in consultation with registered medical practitioners, is setting a framework in guidance. The CMO has established a Short-Life Working Group on Terminal Illness for Disability Assistance. The Group is responsible for developing the CMO's Guidance for registered medical professionals to make clinical judgements about 'terminal illness'. The Group is chaired by Dr Linda de Caestecker, Director of Public Health, NHS Greater Glasgow and Clyde, and its membership goes further than required by the Act. Members include a GP, Consultant in Occupational Medicine, Consultant in Public Health, Consultant Occupational Physician, Consultant for Cancer and Palliative Care, Consultant Geriatrician, Neurologist, Occupational Therapist and academics.

A Reference Group (SHRG) has also been established to enrich the development of the draft guidance. It comprises wider stakeholders to provide the perspective of users and their carers during the development of the CMO Guidance. The Group is chaired by Mark Hazelwood, Chief Executive Officer, Scottish Partnership for Palliative Care and its members include Marie Curie, MND Scotland, the ALLIANCE, MS Society Scotland, Macmillan Cancer Support, Hospice UK, the British Heart Foundation, Parkinson's Scotland, Citizen's Advice Bureau and Chest Heart and Stroke Scotland.

The groups have finalised an initial draft of the guidance, which is concerned with determining whether a person has terminal illness which provides eligibility for disability assistance on the basis of special rules. Its starting point is to determine whether it is the clinical judgement of the registered medical practitioner involved that the person has a progressive condition, which can reasonably be expected to cause the person's death. In addition, it considers whether the individual requires expedited access to Disability Assistance arising from that condition.

The guidance allows for the decisions of registered medical practitioners to be based on their clinical judgement, taking account of a set of relevant indicators, such as if the disease is advanced, if the disease is progressive with decreasing reversibility, if there will be deterioration of an incurable condition and so on. The guidance is now subject to a managed consultation process. Given the clinical nature of the guidance, it has been issued to a wider group of medical professionals as well as representatives of support and advocacy organisations whose views will inform its continued development.

Registered Medical Practitioners, who certify that their patient is terminally ill and is eligible for benefits under special rules will complete the Benefits Assistance under Special Rules in Scotland (BASRiS) form (replacement of DS 1500 for benefits devolved to Scotland – see interactions with 'UK legislation and other definitions' below) and submit it to Social Security Scotland.

Special Rules

If eligible for special rules, the individual's application for Disability Assistance will be processed differently by Social Security Scotland. 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.
- Individuals who qualify under special rules will be automatically entitled to the highest rate of the component part(s) (care and mobility) of whichever benefit they are entitled to.

This may also enable the person's carer to access Carer's Allowance quicker, as this is a 'passport' benefit, dependent on the person receiving one of the disability benefits.

Interaction with UK legislation and other definitions

The UK Government ask medical practitioners to complete a 'DS 1500' form to determine if someone is regarded as terminally ill for disability benefit purposes. Terminal illness for the purposes of the DS 1500 form is defined in UK Social Security legislation as above. The special rules entitle individuals to the highest rate of care, but not mobility. It is also subject to a review period of 3 years.

The Scottish Government is working to ensure that those who already have a completed DS 1500 do not require a separate BASRiS form to be completed for Disability Assistance in Scotland. We propose that their entitlement will be automatically recognised and transferred to the Scottish system, without them needing to take any action. When they transfer to the Scottish Government they will access Scottish Government rules, including receiving the highest rate of mobility assistance and not being subject to review.

As the Scottish Government system will pay higher awards than the DWP for some people, we will prioritise the transfer of people regarded as terminally ill who are not in receipt of the highest rates, and move their cases into Social Security Scotland as soon as it is safe to do so. People eligible for higher awards will receive these awards from the point they transfer to the Scottish Government.

We recognise that the legislative landscape is complex and some people will be working with different requirements and definitions for different purposes and that this has the potential to cause confusion. We will ensure that our communication about this new definition is clear and to do our best to ensure that individuals understand that this new definition is for the purposes of determining eligibility for Disability Assistance only.

Next Steps

The managed consultation on the guidance launched on 12 February and it will close on 19 April. The groups established by the CMO will consider these responses and further develop the guidance as necessary. The guidance will be published in advance of Social Security Scotland delivering the first form of Disability Assistance.

Scottish Government
Social Security Directorate
February 2019

All enquiries in relation to this paper should be sent to:

Claire McDermott
Claire.McDermott@.gov.scot
2F-South Victoria Quay



Scottish Government
Riaghaltas na h-Alba
gov.scot

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Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78781-633-6 (web only)

Published by The Scottish Government, February 2019

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS545606 (02/19)

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