

WELFARE REFORM COMMITTEE

THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND

WRITTEN SUBMISSION FROM MARIE CURIE

Introduction

We welcome the opportunity to respond to the Welfare Reform Committee's Inquiry into the future of social security in Scotland. Marie Curie's vision is for a better life for people and their families living with a terminal illness. Our mission is to help people and their families living with a terminal illness make the most of the time they have together by delivering expert care, emotional support, research and guidance.

What do we want to see?

We believe that the welfare system should help enable those living with a terminal illness to enjoy as a high quality of life as possible until they die.

This means utilising the benefits system to provide those with a terminal illness, and their carers, with the necessary financial assistance, alongside their health and social care support, to live well.

Benefits for those living with a terminal illness should be delivered quickly and with limited disruption to their lives. They should look to mitigate the cost of living with a terminal illness, and prevent any fall into poverty and social isolation at end of life.

The welfare system and its administrators must be compassionate and sensitive to the nature of dealing with someone who is terminally ill and approaching the end of their lives, as well as their carers who are often family members and loved ones.

Improving the benefits system in Scotland

To achieve this, we believe the Scottish Government should consider the following in developing a future approach to social security in Scotland:

- Far too many people living with a terminal illness are not currently getting the benefits they need to support themselves. We want to see all those living with a terminal illness get the support they need and is available to them, including financial assistance.
- All benefits for those living with a terminal illness should be received quickly – no more than 7 days from time of application to receipt.
- Benefits should be of a sufficient level to support people to live well for as long as possible.
- The benefits system must be easy to navigate, so that people can establish what they might be entitled to and how to apply for it. The application process must also be simple.
- There needs to be good, clear and accessible information to support people to access the benefits system. Current information is not always clear or consistent and can hinder a person's ability to maximise their support across the various statutory bodies.
- No one living with a terminal illness should be required to work. However, it may be that a person chooses to keep working. The welfare system should support both.

- Carers of those living with a terminal illness should receive assistance to allow them to fulfil their caring role. They should also receive that support quickly – no more than 7 days from time of application to receipt.
- We would like to see greater research carried out into the cost of living with a terminal illness and how access to benefits can alleviate this.
- There needs to be a consistent application of the welfare system across Scotland with no postcode lottery of support.
- Those on low incomes struggling to pay for funerals should receive adequate financial support so as to be able to pay for a basic funeral for their loved ones.

Living with a terminal illness

54,000 people die every year in Scotland many of whom have been living with a terminal illness, such as terminal cancer, heart disease, dementia, motor neurone disease, frailty, and in many cases they will be facing a combination of two or more of these conditions.

Coming to terms with a terminal diagnosis can be a very difficult time for a person and their families. Depending on the nature of their condition they can live for years, months, weeks or days following their diagnosis. It will have a significant impact on their working and home life.

Current benefits available to those living with a terminal illness and how the future of Social Security in Scotland

Those living with a terminal illness may qualify for the following benefits:

- Personal Independence Payment (PIP) if they are aged between 16-64– (some existing patients may be in receipt of the Disability Living Allowance (DLA)) Currently 9% of PIP claimants are classed as being terminally ill in the UK.
- Attendance Allowance if they are aged over 65 - in Scotland 2,920 people living with a terminal illness claimed Attendance Allowance (February 2015).
- Employment and Support Allowance,
- There are also a range of passported benefits available to those living with a terminal illness including Energy Efficient Grants, Warm Home Discount Scheme, a blue badge for parking.

Personal Independence Payments, Disability Allowance, Attendance Allowance and Carer's Allowance

People living with a terminal illness in receipt of the DS1500 can receive their benefits under special rules including:

- the enhanced rate of the daily living component of PIP straightaway/higher rate of Attendance Allowance
- applicants don't have to show that they have difficulty carrying out daily living activities
- applicants don't have to meet the required period condition
- applicants don't have to attend a face-to-face assessment.

For those not in receipt of a DS1500 that are living with a terminal illness they may still qualify for PIP or Attendance Allowance, but will need to apply in the normal way.

For PIP, applicants will need to have had daily living needs or mobility needs for at least three months, and be expected to continue having these needs for at least another nine months. Even if the person has a terminal illness, they still have to claim in this way if they do not have a DS1500.

Both PIP and DLA include a mobility component. Applicants won't automatically get this under the special rules. The normal rules of assessment still apply for this, but not the usual three month qualifying period.

For Attendance Allowance without a DS1500 applicants must set out how they need care in their claim form. This can include things like help or support with getting in and out of bed or needing supervision to prevent danger to themselves or others. They may have a visit from a doctor or healthcare professional approved by the DWP or SSA to report on your needs. This process can take several months.

We would urge the Scottish Government to ensure that these special rules continue to apply when these benefits are devolved and apply to any new or replacement benefits introduced by the Scottish Government.

Problems accessing benefits for those living with a terminal illness

Marie Curie believes that many people with a terminal illness are not always accessing the benefits they are entitled to or receiving them as quickly as they should.

There are many people living with a terminal illness who might qualify for a DS1500, but do not receive it, which means that they would have to apply for benefits in the usual way or miss out altogether.

Although the DS1500 can be useful it is also limited. DS1500 are issued to those, deemed by a GP, to be in the last 6 months of life. There are many terminal conditions where it can be difficult to predict when a person has entered the last 6 months of life, but still may die. There is some evidence that suggests that DS1500s are more likely to be issued to those terminally ill with cancer, compared to those with other conditions¹.

Statistics from the DWP show that that for people accessing PIP via the special rules for terminally ill people, 95% have a malignant condition². Although we don't know if people with non-cancer conditions are already accessing PIP through 'normal' routes, this high percentage suggests that there is an association between terminal and cancer which could mean people with other terminal conditions are missing out on the sped up and ease of access of benefits. Marie Curie believes that this requires further investigation.

We would urge the Scottish Government to review the role of the DS1500 in supporting people living with a terminal illness to access higher-rate and fast tracked benefits to ensure this is meeting the needs of all people living with a terminal illness in Scotland regardless of condition.

Those applying without a DS1500 may have to wait a significant amount of time before receiving their benefits, which can be considerably distressing for them and their families. In some instances recipients have been known to die, whilst waiting to receive their benefits.

¹ State financial assistance for terminally ill patients: the discrepancy between cancer and heart failure, BJC March 2010, Volume 17, Issue 2, Br J Cardiol; 17:73–5

² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/434838/pip-stats-apr-2013-apr-2015.pdf

The welfare system at present can be very challenging for new applicants. There is often a stigma, and an underlying level of mistrust, which can have an impact on those in need of help.

We have also heard of cases of people being questioned about the length of time they expected to live for, despite being in receipt of the DS1500 and qualifying for PIP under the special rules³.

Carer's Allowance

Those caring for someone with a terminal illness can face substantial pressures, particularly as the patient's condition deteriorates and the care needed becomes increasingly complex and time consuming. Adequate support for carers is essential in order to help them maintain their caring role. Without it carers are at an increased risk of breaking down, which can have a substantial impact on their health, but on the care of the patient too. The patient may have to be hospitalised to continue their care, which comes at a considerable cost to the state and also not where they would want to be.

At the end of life the role of the carer is fundamental in ensuring that a person can stay at home, if that is where they wish to be. Evidence shows that having a carer is the single most important factor in enabling a person to be cared for at home. We need to ensure that we develop a welfare system and a society that enables carers to care, without creating an environment that is detrimental to that.

Many people caring for someone with a terminal illness will have to give up work. The amount currently offered to carers under the Carer's Allowance, will be for many, substantially less than they receive for employment. This coupled with the fact that the person they are caring for will have also been forced to give up work. This can have a significant detrimental effect on the income of the household.

There is no income taper for the Carer's Allowance. This means a person may have an income of £109 per week and be entitled to full Carer's Allowance, whilst a person with an income of £111 is not entitled to any. We believe that this needs to be changed.

Marie Curie believes that the proposed devolution of the Carer's Allowance in the Scotland Bill needs to be amended.

We believe that the Scottish Government should set the criteria for the devolved carer's allowance. We also believe that the definition of a carer must be the same as one set out in the proposed Carers (Scotland) Bill, which is currently going through the Scottish Parliament.

At present there is no mechanism for the Carer's Allowance to be fast tracked. We believe that the Scottish Government should look to enable those caring for someone living with a terminal illness to have their Carer's Allowance fast tracked under similar special rules, as those set out for people with a terminal illness claiming PIP/Attendance Allowance.

Universal Credit (housing element and administrative arrangements) and Discretionary Housing Payments

There is anecdotal evidence that suggests that those living with a terminal illness have been affected by the 'bedroom tax'.

³ <http://www.theguardian.com/politics/2015/jul/06/terminally-ill-benefit-claimants-asked-when-they-expect-to-die-mp-says>

Depending on the nature of the condition a person may need a second bedroom for to sleep in. This may be because they need a special medical bed, or a large amount of equipment to support them to sleep.

For those in receipt of Housing Benefit may have fallen foul of the 'bedroom tax' and be reliant on the Discretionary Housing Payment. Marie Curie would be supportive of the Scottish Government maintaining this payment and ensuring that all those living with a terminal illness in need of a spare room are getting adequate housing support.

The Work Programme and Work Choice

When time is short, a person should be able to enjoy as high a quality of life as possible, and should not be required to work if they do not want to.

Some people with a terminal illness have been deemed fit to work by the DWP and required to work or seek work. Although many people living with a terminal illness are keen to continue working, as they see it as an important part of their lives, they should never be compelled to work. Figures released by the DWP on 27th August 2015 have suggested that thousands of people over the last four years have died shortly after being declared fit for work.

This is unacceptable and we would urge the UK Government to look at the Welfare system and how the fit-for-work assessment process is carried out.

Marie Curie would also urge the Scottish Government to explore options to help mitigate the impact of people living with a terminal illness in Scotland potentially being declared fit for work.

The Regulated Social Fund, new benefits, top-ups and delivery of benefits overall

Many people in Scotland are not able to afford the cost of a basic funeral for their family.

Research from the University of Glasgow shows that the percentage of households falling below society's minimum standard of living has increased from 14% to 33% over the last 30 years with 800,000 people too poor to engage in common social activities, such as funerals. The average total cost for a basic funeral in Scotland in 2014 for a cremation was £2,610 and £3,240 for a burial. These costs have risen at a rate of 7% year on year since 2004. These bereavement rites are simply unaffordable by some bereaved families leaving some unable to bury their deceased.

Research by Citizens Advice Scotland has also found that burial and cremation costs vary substantially across Local Authorities in Scotland. Burial costs range from £680 to over £2,500 and cremation costs from £485 to £730 across Scotland. This makes it difficult to plan for the costs of a funeral either for an individual or a bereaved family, especially as almost one in three people (30%) cannot afford to heat their homes adequately in the winter.

We would urge the Scottish Government to ensure that any future Funeral Payment ensures that those on low income can afford a basic funeral for their family members. This payment must also reflect the location of the claimant and the different levels of cost. The fund must also be adequately resourced so that people can claim all year round, wherever they live.

Other Scottish Benefits for those living with a terminal illness

It is important to ensure that all those who are under 65 and terminally ill are receiving the social care benefits they are entitled to currently in Scotland, including free personal and nursing care. There is still evidence to suggest that this is not always the case.

We need better data collection on benefit statistics to ensure we understand the picture of welfare in Scotland. There is at present little Scottish data looking at the receipt of benefits for people with terminal illnesses.

Marie Curie would urge the Scottish Government to carry out research into the financial and benefit support given by the state to those living with a terminal illness and their carers. This would allow the Government to understand the complete picture and to put in place plans to ensure that the support given to this very vulnerable group of people is sufficient to enable them to live as well as they can in the time they have left.