



Care and support
through terminal illness

Marie Curie Response

Dignity, Fairness and Respect in Disability Benefits

Marie Curie cares for over 8,000 people living with a terminal illness, their families and carers across Scotland through our hospices, community nursing services and support services. We treat people with all terminal conditions, whether that is terminal cancer, dementia and frailty, Motor Neurone Disease, Multiple Sclerosis, chronic obstructive pulmonary disease or heart failure.

We believe that Scotland's new social security system must support those that are living with a terminal illness and their carers to live as a high quality of life as is possible in the time they have left.

Marie Curie urges the Scottish Government to ensure that:

- **All devolved benefits to continue to include a system of fast tracking for those living with a terminal illness**
- **Carers of terminally ill people also be entitled to fast tracked benefits, such as Carers Allowance.**
- **Any new benefit introduced to include a system of fast tracking for those who are living with a terminal illness.**

A fair system for people living with a terminal illness

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. 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.

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.

Marie Curie supports the Scottish Government's proposal of putting dignity, fairness and respect at the heart of a new social security system in Scotland

Improving the benefits system in Scotland

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.

Current benefits (due to be devolved) available to those living with a terminal illness and their carers

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.
- Carers 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 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.

Statistics from the DWP show that that for people accessing PIP via the special rules for terminally ill people, 95% have terminal cancer¹. 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 fast tracked benefits. Marie Curie believes that this requires further investigation.

We 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.

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 rules².

It has also been reported by the Public Accounts Committee at Westminster that the average waiting time for people living with a terminal illness to receive a decision on PIP was 28 days – 180% longer than originally expected. This is not acceptable and must be improved as a matter of urgency.

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.

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.

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

¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/434838/pip-stats-apr-2013-apr-2015.pdf

² <http://www.theguardian.com/politics/2015/jul/06/terminally-ill-benefit-claimants-asked-when-they-expect-to-die-mp-says>

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. 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. We also believe that Carer's Allowance should be set at the same rate as Job Seekers Allowance.

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.

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 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.

Further information:

We are happy to provide further information to support this consultation. For more information, please contact:

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