



Care and support
through terminal illness

Marie Curie Response

Consultation on Social Security (Scotland) Bill Stage One – August 2017

Introduction

1. Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our six volunteer led Helper services. We also provide nationwide support through our information and support service including our national helpline.
2. Last year we provided care for 8,394 people living with a terminal illness, as well as their families and carers across Scotland.
3. 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 living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.
4. Many of the people we care for and their families will be in receipt, or could be in receipt of one or more of the social security benefits that are due to be devolved to Scotland, including the Personal Independence Payment (PIP), Attendance Allowance and the Funeral Payment. Their carers may be receiving Carers Allowance.

The General Principles of the Bill

5. Marie Curie supports the general principles of the Bill.
6. However, we have some concern that so much of the legislation relating to the make-up and rules of the new Scottish Benefits will be decided through regulation.
7. Firstly, Parliament will only have the power to accept or reject regulations, leaving little room for amendments or changes that might be identified throughout the legislative process.
8. Secondly, regulations could make it far easier for a future Scottish Government to make significant changes to the benefits system without proper scrutiny by the Parliament in the way that primary legislation is scrutinised. We would urge the Committee to give this considerable thought when delivering its recommendations for its Stage One report.

The proposed seven principles of the Scottish social security system

9. Marie Curie supports the proposed seven principles of the new social security system as set out in the Bill.
10. Marie Curie believes that, as in health and social care, there should be a person-centred approach to social security. When someone's health is at risk or compromised it has been widely accepted that a person centred approach that puts the person at the heart of their own care brings about the best outcomes for them. This is set out very clearly in a number of Scottish Government national health strategy documents and frameworks including the Quality Strategy.

11. The social security system and its benefits, particularly those due to be devolved to Scotland, are there to support those people with disabilities and long term health conditions. We believe that in order to be complimentary to the health and social care system and to ensure the best possible long term outcomes for those in receipt of benefits and support. The new social security system should also take a clear person-centred approach. We believe this should be encapsulated on the face of the Bill and incorporated into the listed principles for example:

- a. *The Scottish social security system will take a person-centred approach to designing, implementing and administering social security assistance for all those eligible.*

Social Security Charter

12. Marie Curie supports the proposal of a social security charter.

13. Under section 3, Preparing the first charter, we would urge the Bill to include those in receipt of fast tracked benefits under special rules for terminal illness. We are concerned that due to the difficult nature of recruiting those with a terminal illness to such a consultation exercise that their views will not be sought or made easy for them to be given. We would like to see the Bill amended to specifically include those claiming social security with a terminal illness to be consulted, for example, under 3 (3):

- a. *(h) those in receipt of any benefit under special rules for terminal illness.*

Disability assistance for those living with a terminal illness

14. Marie Curie supports the specific inclusion of terminal illness as a reason for someone receiving disability assistance.

15. We would like to see the Bill amended to include a guaranteed system of fast tracking for disability assistance given on an account of someone having a terminal illness. Many families can face considerable short term costs following a terminal diagnosis, on top of considerable psychological and physical distress. Someone with a terminal illness should receive the support they are entitled to as quickly and easily as possible.

16. This could be included under 14 (2) of the Bill with the following amendment:

- a. *(c) a system of fast tracking for disability assistance for those individuals with a terminal illness.*

17. The current Scottish Government has stated on a number of occasions that it supports a system of fast tracking benefits. Most recently the First Minister reiterated her support at an MND Scotland event at the Scottish Parliament stating:

"When we take responsibility for delivering the benefits... we will put in place a fast-track system to end the delays that people too often experience right now.

"That will ensure that disability payments reach people with terminal illnesses as quickly as possible."¹

18. We also believe that anyone appealing a claim decision made because of having a terminal illness should have the appeal process fast tracked too. Section 24 of the Bill should be amended to include a specific reference to a fast tracked approach for those having a terminal illness appealing a decision.

¹ <http://thirdforcenews.org.uk/tfn-news/terminally-ill-to-get-benefits-fast-tracked>

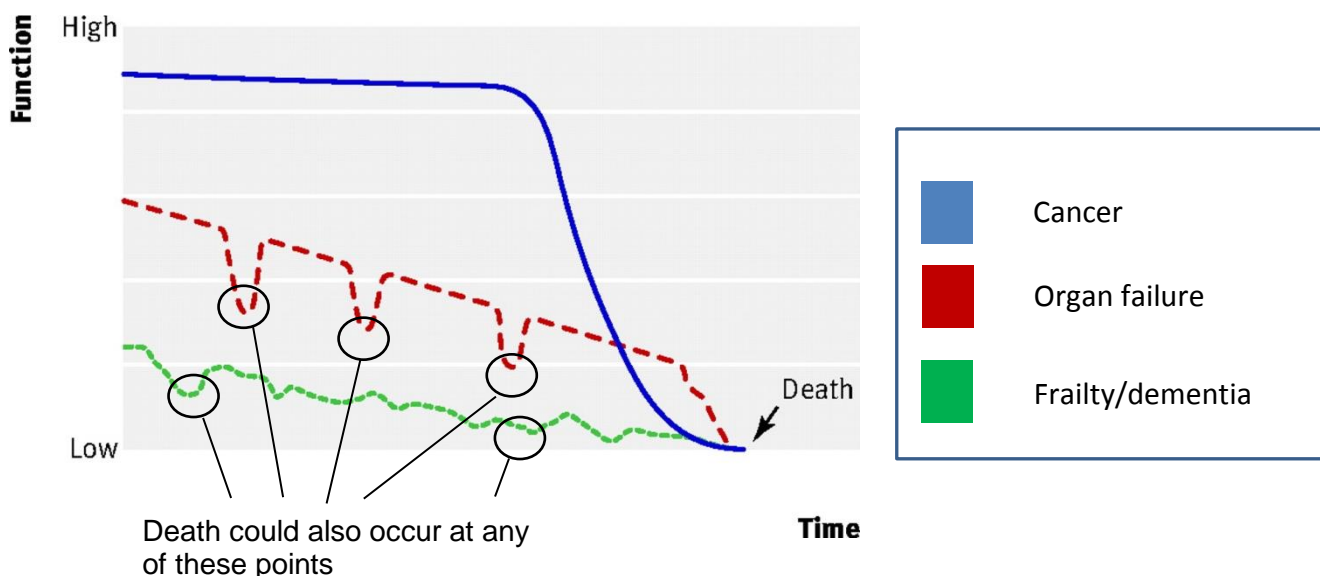
Support for Carers

19. Marie Curie supports any increase in financial support for Carers, and as such we support the proposal to increase the level of Carers Allowance from £62.10 to £73.10 a week.
20. However, we do not believe that the proposed level is high enough to effectively support carers financially. Job Seekers Allowance (JSA) is a short term benefit designed to help a person seeking work to bridge the gap between pay days. The level of payment is not designed to meet the full living cost of someone, but to help them until paid work can be found. Those in caring roles in receipt or eligible for Carers Allowance are not likely to be in short term caring roles nor likely to be looking for work, the fact that the eligibility criteria currently requires carers to be carrying out 35 hours a week of caring is evidence of this. Carers need real support to allow them to carry out their caring role to the full.
21. Marie Curie believes that carers should receive a significantly higher level of financial support than JSA. We believe that as a society we must value our carers who provide irreplaceable levels of support to family, friends and loved ones. Many are not in a position to cover the financial costs incurred caring for someone and will rely on statutory support, such as Carer's Allowance, as well as other benefits received by those they are caring for. Without these carers, health and social care services would incur significant additional pressures and costs. We believe that the new social security system presents us with an opportunity to discuss and debate the real value that Carers add to our society and how we should support them, including financially, to do this.
22. Schedule 1 sets out the terms of the Carer's Assistance Regulations. Marie Curie believes that any future carer's benefit should be a benefit in its own right and should not be dependent on whether or not the person being cared for is in receipt of a disability benefit or not. We believe that not only would this ensure that more people received the benefit who need support, but that they would receive it sooner, as they would not need to wait to apply for the benefit until the person they were caring for received their disability benefit. We believe this could be potentially linked to the recently passed Carers (Scotland) Act and the Carers Support Plan.

Defining terminal illness for social security assistance

23. Schedule 4 relates to the Disability Assistance regulations and sets out that the regulations will define 'terminal illness' for the purpose of determining entitlement to disability assistance. We would like to see the definition of terminal illness included on the face of the bill.
24. At present the definition for terminal illness used to support application for disability assistance in the UK is taken from the Welfare Reform Act 2012 defining a terminal illness as someone in the last 6 months of life². We believe that this is inadequate and does not meet the needs of people living with a terminal illness.
25. There are many terminal conditions where it can be difficult to predict precisely when a person has entered the last 6 months of life. The chart below shows the different trajectories towards death by terminal illness and how some can be stable and predictable, but others can include episodes of decline and recovery. These may include conditions such as heart failure, dementia or COPD. A person may be expected to live for five years with their terminal illness, but may die within six months of that prognosis being given, due to a sudden decline in their condition.

² <http://www.legislation.gov.uk/ukpga/2012/5/section/82/enacted>



26. At present under the current DWP system many people living with a terminal condition will not qualify for the special rules for social security benefits, as they have been deemed not to be in the last six months of life. This means that they do not get their benefits fast tracked, they will have to undergo rigorous and intrusive assessment processes in person, and will not necessarily get the higher element of the disability payment. Yet the terminal nature of their condition would suggest that they should receive their benefits under special rules.
27. For example, people diagnosed with Motor Neurone Disease (MND) have an average life expectancy of 14 months and will begin to see a deterioration in their condition from that point. To make someone with MND apply for social security benefits in the normal way appears somewhat insensitive to their condition, especially when there is a clear diagnosis and likely prognosis. According to MND Scotland those accessing PIP without a DS1500 (the form needed to claim for benefits under special rules for terminal illness) can take up to six months³.
28. At present, the system of special rules is only working for people with a terminal cancer diagnosis. Statistics from the DWP show that that for people accessing PIP via the special rules for terminally ill people, 95% have terminal cancer⁴. Yet, only 28% people die of a cancer each year. This shows that there are flaws with the current system, which Scotland has an opportunity to get right in developing its own social security system.
29. We believe that using a definition of terminal illness that only includes those in the last 6 months of life unfairly excludes many people living with terminal conditions for accessing the benefits they need quickly and easily.
30. We would like to see the Social Security (Scotland) Bill amended to include a definition of terminal illness in the Bill and not regulations. Not only will this provide a clear point of reference for all benefits administered by the new social security system in Scotland, but can be used by other legislation, regulation and policy that is developed in Scotland that needs to refer to a definition of terminal illness.
31. Any definition of terminal illness included in the Social Security Bill should not include a restriction by life expectancy, but should be based on need.
32. We would urge the Scottish Government to establish an Expert Reference Group to develop a definition of terminal illness that can be considered as an amendment at either Stage 2 or 3 of the Bill.

³ <http://www.mndscotland.org.uk/wp-content/uploads/2016/10/Lets-Get-Benefits-Right-Full-Consultation-MND-Scotland.pdf>

⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/434838/pip-stats-apr-2013-apr-2015.pdf

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