Campaign for fairer access to benefits for people living with a terminal illness

Marie Curie is working with the MND Association to change the definition of terminal illness in the UK to make it easier for people to access financial support when they are dying.

Many people at the end of their lives rely on financial support as they can no longer work, or because of the increased costs associated with living with a terminal illness. A recent inquiry into benefits access by the All Party Parliamentary Group for Terminal Illness found that the additional cost of living with a terminal illness was between £12-16k per year.

In the UK, the Special Rules for Terminal Illness allow people faster than standard access to several benefits at the highest available rate, but only if they can prove they have six months or less to live.

Estimating how long an individual might live is difficult and many GPs and healthcare professionals don't feel comfortable saying someone has six months left to live. The six months rule has no clinical basis or evidence.

Many terminally ill people end up going through the standard bureaucratic process, which can take on average 16 weeks. Many will have to undergo an assessment of their fitness to work or even prove that they are looking for work.

No one who is dying should be forced to look for work to get the financial support they need. No one should face a 16 week wait for financial support when their remaining time to spend with their loved ones is so short. **No one should be negotiating Government red tape at the end of their lives.**

We are seeking to bring the Access to Welfare (Terminal Illness Definition) Bill back to Parliament to amend the Welfare Reform Act 2012, which defines terminal illness as having six months or less to live. The Bill will instead allow healthcare professionals to determine – alongside guidance – when someone is terminally ill. 51% of GPs support this change according to independent polling, with only 12% opposing it.

The DWP have said that they consider the sixmonth rule 'flexible' and have amended their guidance for clinical professionals. However, by the letter of the law it is not, and many GPs and healthcare professionals feel that they must be absolutely certain that someone is in the last six months of life.

If the six-month rule is truly flexible, it makes sense to bring legislation in line and give GPs and healthcare professionals the certainty that they need to help people with a terminal diagnosis access the support to live as well as possible until they die.

In Scotland, we have successfully campaigned to change legislation so that doctors will soon be able to use their clinical judgment (alongside Government-issued guidance) to determine who should be considered terminally ill for some benefits (UC and ESA are reserved benefits, so still fall under the Westminster rules).

136 cross-party MPs support this legislation. More than 55,000 members of the public signed a petition to ask the Government to scrap the six month rule and the campaign has received huge positive media coverage,

including in the <u>Daily Express</u>, <u>Daily Mail</u>, <u>Sun</u>, <u>Huffington Post</u>

This campaign is an opportunity for the Government to turn the UK into a world leader in delivering compassionate and timely financial support to people who are dying.

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