

## Response to the consultation on the future of the Independent Living Fund

### Introduction

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

### Question 1

**Do you agree with the Government's proposal that the care and support needs of current ILF users should be met within the mainstream care and support system, with funding devolved to local government in England and the devolved administrations in Scotland and Wales? This would mean the closure of the ILF in 2015.**

- i. The consultation paper describes a social care system that has been transformed to be more personalised and responsive over the last two decades. While a shift to personalisation has indeed happened, the major change to have taken place in the social care system is that it has become ever-more dysfunctional owing to a lack of funding. The nature of the crisis in social care is well-documented and will not be detailed here, but it is not lost on us that the entire rationale on which these proposals are supposedly based is false.
- ii. The closure of the ILF therefore represents not the long-due retirement of an outmoded model of care, but the denial of vital support to many ill and disabled people. As the scheme has been closed to new applicants since 2010, relatively few of the surviving ILF users will be people with MND (most recipients with MND will have died since then); but for people more recently diagnosed with MND, financial support they would once have benefited from is

not available, and no attempt has been made to replace it. The consultation paper notes that the average award for a 'group 2' user is £368 a week, compared to a social care entitlement of £536; the loss of the ILF element is therefore very considerable.

- iii. While existing ILF users will continue to receive additional support, the result will undoubtedly be a two-tier system: those who were getting ILF funding before the closure to new applicants will continue to get more support than those who were not. This situation discriminates against people with rapidly degenerative conditions, who will be disproportionately represented in the latter group.

### **Question 3**

**What impact would the closure of the ILF have on Local Authorities and the provision of care and support services more widely? How could any impacts be mitigated?**

- i. We would like to see more detail of how local authorities will cope with their new responsibilities. Will they each have to establish new processes for disseminating the money? Will the money be ring-fenced? What will the reassessment of people by the ILF and local authorities entail?
- ii. Surviving people with MND currently receiving ILF funding will inevitably be seriously ill by the time the new system comes into operation. Given that their needs cannot have decreased since they were initially awarded ILF support – reversal of the progression of MND is a medical impossibility – we strongly recommend that they are granted support under the new system without reassessment. Any such reassessment would be unjustifiably distressing, and would tell the local authority nothing new.

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