

£100,000 funding for legal support to ensure people with dementia can access rights

Submitted by: Life Changes Trust

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£100,000 funding has been awarded to Scottish charity MECOPP, to provide legal support to people affected by dementia to help them access their rights to self-directed support.

Self-directed Support (SDS) gives people the power to decide how to spend the money or 'budget' that has been allocated to them if they have social care needs. It enables them to make informed choices on what their support looks like and how it is delivered, rather than decisions being made solely by local authorities on their behalf.

At the heart of self-directed support is choice. For example, local authority provision for assistance with evening meal preparation or getting ready for bed may only be at fixed times, and sometimes very early in the evening. This means that someone who needs these services could find themselves having dinner and being in bed hours before they would normally do so. Self-directed support can give that person the choice to eat when they are actually hungry and go to bed when they are tired.

However, many people with dementia and their families find they are not able to access SDS, or are not offered all four options available within SDS, which can mean they end up with little choice over the kind of support provided, and how and when it is delivered.

This means that they are not being afforded their basic entitlements under the Social Care (Self-directed Support) (Scotland) Act 2013.

The £100,000 funding will be used by MECOPP to provide legal support and advice to people with dementia and their carers in Scotland, where they feel that they have not been dealt with fairly. Where necessary, they will be supported to challenge decisions or the improper use of legislation. For example, someone living with dementia may have been offered reduced options due to their condition, or excluded from choosing SDS altogether.

Advice will also be available to people with dementia and their carers to better understand their rights and their options.

Funding has come from the Life Changes Trust, an independent Scottish charity set up with a Big Lottery Fund endowment of £50 million to improve the lives of two key groups in Scotland: people affected by dementia and care experienced young people.

Anna Buchanan, Director of the Life Changes Trust dementia programme said: "This project is about fairness, equal access and the human rights of people living with dementia. People with dementia should not be alienated from their rights simply because of their diagnosis. The project will provide them with advice and support that could make the difference between having support and not having it."

Suzanne Munday, Chief Executive of MECOPP, said: "The funding award marks a very important milestone in enabling people living with dementia to have full and equal access to self-directed support. A diagnosis of dementia should not adversely affect rights and entitlements which are enshrined in legislation. We

look forward to working in partnership with the Life Changes Trust, people living with dementia and dementia support organisations to achieve real change.”

ENDS

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EDITORS NOTES:

Our work with people with dementia has shown that the phrase “Dementia sufferers”, or using the word suffering to describe dementia has a strongly negative view from people with the condition. We would request that you avoid using the phrase in headlines or in any article you publish to combat the negative way that people with dementia feel the condition is described.

MECOPP: By working in partnership with carers, the voluntary and statutory sectors, MECOPP actively seeks to challenge and dismantle barriers that deny Black and Minority Ethnic carers and carers from other marginalised communities access to health, social work and other social care services in Edinburgh, the Lothians and further afield.

This funding has been awarded to MECOPP as they have previously carried out successful work around Self Directed Support. In this instance, this funding does not focus exclusively on ethnic minority older people, but on anyone with dementia in Scotland.

The Life Changes Trust was established by the Big Lottery in April 2013 with a ten year endowment of £50 million to support transformational improvements in the quality of life, well-being, empowerment and inclusion of people affected by dementia and young people with experience of being in care.

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