

Game-changing investment in people affected by dementia

Submitted by: Life Changes Trust

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A ground-breaking investment of £2.5 million has been announced by the Life Changes Trust to create a School of Leadership in Dementia and a National Forum for Dementia Policy and Practice. Both initiatives will support people with dementia and carers to become experts, leaders and influencers in Scotland.

Scotland has already led the way with its three National Dementia Strategies. The creation of the National Forum will bring together people with experience and expertise in dementia, locally and nationally, with the aim of evidencing what will create better lives for people with dementia and unpaid carers. The Forum will provide space to scrutinise policy and practice in many areas, including housing and dementia, sport and dementia, the arts and dementia, and human rights and dementia.

The Forum will promote evidence of what works well so that national and local policy and practice can be reviewed and, where necessary, adjusted. This is so that Scotland can become an exemplar of how, in all aspects of life, people with dementia can find meaning, be fully supported and involved.

The School of Leadership will bring together people with a particular interest and experience in the subject of dementia to develop their leadership skills so that they can be integral to leading positive change at all levels of society.

The School of Leadership and the Policy and Practice Forum will be delivered collaboratively by Age Scotland, the University of Edinburgh and Queen Margaret University.

Anna Buchanan, Interim CEO of the Life Changes Trust, said, “The School of Leadership and the Forum will, in due course, change the landscape of the dementia world in Scotland. They will create a strong network of people with shared values and purpose, supporting them to make a major contribution to transforming the lives of people with dementia and unpaid carers. Both projects are vehicles that will support and encourage people with dementia and their carers to flourish and develop, gaining leadership skills and confidence to have their voices heard in a way that will have real impact. They will ensure the needs of people with dementia, their families and unpaid carers are met and their lives fundamentally transformed for the better.”

Professor Brendan McCormack, from Queen Margaret University and Professor Heather Wilkinson from the University of Edinburgh said, “Being a part of this ground-breaking development to work with people living with dementia and their carers advances the potential for all people in all communities to reach their full potential. Our work focuses on helping all people to flourish and the Life Changes Trust School of Leadership and Policy & Practice Forum will equip people living with dementia to shape their lives and communities in ways that really matter to them. Having those with lived experience leading and shaping future policy and practice is essential if we are to change their experience for the better. Both projects will build on and advance existing good practice and grow the potential of new, future leaders to make a real difference to people’s lives.”

Brian Sloan, Chief Executive of Age Scotland said, “For many people in Scotland living with dementia and their carers, a one-size-fits-all approach to their care does not always take into account the vital

aspects of their everyday life and well-being. This needs to change. We are incredibly proud that so many wonderful organisations are partnering with us to deliver this ground-breaking initiative. People affected by dementia will be at the heart of this work, and together we will identify and demonstrate what works in terms of human rights, peer support, early intervention, prevention and a relationship-centred approach to care. We will ensure that policy makers, service providers and the public know what matters to people affected by dementia and use the evidence we produce to show how to make Scotland a better place to live.”

The Life Changes Trust was 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.

ENDS

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NOTES TO EDITORS:

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.

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.

In Scotland:

- It is estimated that around 90,000 people have dementia.
- The number of people with dementia in Scotland is increasing, because the population is getting older. Based on current dementia prevalence rates, the number of people with dementia in Scotland is projected to double by 2038.
- Dementia costs the country more than cancer, heart disease and stroke put together.

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