



Alzheimer's Society in Northern Ireland statement:

Operations Director Bernadine McCrory said:

“The Alzheimer's Society would like to see a review of the dementia strategy before we would draw conclusions on how the budget was allocated. However, there is currently severe underinvestment in dementia when compared to other serious health conditions like cancer and heart disease, so we would strongly urge the Department of Health to ensure this unspent budget is ring-fenced for further investment in dementia care, research, and awareness-raising.

“It is worrying to see diagnosis rates have stalled, Northern Ireland has been leading the way with diagnosis rates and Alzheimer's Society does not want complacency to set in. The Dementia Strategy Implementation group committed to an objective of all trusts achieving and maintaining 75 per cent in diagnosis rates and this has not been met. This means there are many people being left without a diagnosis and without the information and support available to help them deal with the complexities of their condition.

“There are obstacles to getting a diagnosis. Stigma and fear continue to put many people off seeking medical advice until the condition has progressed considerably. But it is only part of the story. We regularly hear of people having to deal with resistance from their GPs and then experiencing long months waiting for a referral to memory specialists. Delaying much needed information, care and support that can help them to live well for as long as possible.

“Diagnosis rates can be increased with effective awareness raising campaigns so people can recognise the early signs of dementia and seek medical advice, and by reducing the stigma associated with dementia. Additionally medical professionals need to identify symptoms as early as possible and ensure that people are referred to and assessed by a memory specialist as a matter of urgency.

“Getting a diagnosis is hugely important, it may give the person some comfort in being able to attribute their symptoms to a condition, and they gain access to medication where appropriate. It also means the person with dementia and their family have access to a dementia support worker and other Alzheimer Society services which are available to provide support, advice, information to help them through this difficult journey.

“Northern Ireland having a dementia strategy clearly signals that dementia is on the Government’s agenda. It is an invaluable statement of commitment to make things happen to improve the lives of people affected by dementia.

“In terms of the impact of the strategy on people affected by dementia it is harder to say. Alzheimer’s Society led the research involving people with dementia to inform development of the strategy. The Listening Well report, published late in 2009, called for very specific actions-and these came directly from people with dementia living in Northern Ireland.

“People with dementia wanted more professional and public understanding of dementia as a medical condition and more involvement of people with dementia, speaking publicly about their experience to tackle stigma and lack of awareness. We can certainly see the huge positive impact of people speaking on the media about their experience and informing health and social care workforce of how good care feels for the person. This is a very positive change.

“People with dementia who were directly involved in Listening Well research also wanted to see early diagnosis and for diagnosis to be sensitively handled by health professionals with appropriate expertise. They wanted people who have been diagnosed to be referred to services and support that could help them live well and their family carers support them. This is not the case for many people in Northern Ireland. Alzheimer’s Society has long campaigned that early diagnosis should not be reliant on luck or location.

“In 2016 Alzheimer’s Society pressed in its input on Programme for Government for a review of the strategy so that we can see exactly how and how well it affected people for whom it was developed.

“This review/evaluation will show clearly what works, can work better and needs to be promoted to ensure people with dementia feel the effect of a

strategic approach. Of course we are aware of people having positive and supportive experiences-including of diagnosis and post diagnosis support-but we also hear stories where a lack or poor quality services and support added hugely to the difficulties faced by people with dementia and where people felt abandoned to cope alone.

Next steps...

“Dementia is one of the biggest health and social care issues of the 21st century and is set to be the UK’s biggest killer. We know so much more about the condition and the challenges facing people with it. We can see the potential impact on our health & social care system, but also on people and families affected. It is essential that we take a strategic and rights-based approach to the issue.

“The dementia strategy led on development of the new mental capacity legislation which will have a very positive affect on people with dementia but it must be implemented and that requires political will and resources.”