

## Submission to the National Dementia Strategy

August 2012.

### About Us

Care Alliance Ireland is an Alliance of over 90 organisations who support Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life for Family Carers. We achieve this by supporting our member organisations in their direct work with Family Carers through the provision of information, informing and developing research, policy and practice, and instigating opportunities for collaboration.

### Observations/Recommendations

As evidenced in the Creating Excellence in Dementia Report, Family are the most significant providers of care to those affected by dementia. (p12,81) This is likely to continue into the future. As such, strategies that enable Family Carers to continue to provide this care need to be at the heart of any Dementia Strategy.

The report (p13) highlights the particularly high impact 'dementia care' has on many family carers, and their expressed need for relief, support and to be more involved in decision. This speaks to the concept of partners in care, as articulated in the recent National Carers Strategy;(2012)

*'Carers will be recognised and respected as key care partners. ' (Vision Statement)  
'Include carers in care planning and decision making for those that they care for'(Objective 1.2)*

A particular focus should be on the provision of Family Carer Training. The once off dormant funds initiative (2009-2012) whilst welcome, and having demonstrated a positive impact, is coming to an end with no specific proposals to continue with this dedicated funding stream. This is of great concern. Surveys of carers repeatedly highlight the need for information, and as such 'training' can significantly address this need. Training should be delivered in carer friendly formats including in 1-2-1 format as necessary and as requested.

Case management has also been shown to be effective in supporting the person with dementia and their carer. (p77, Excellence in Dementia Report). We argue that, when done sensitively and professionally, and including an assessment of the needs of the carer, the journey of caring can be less demanding and can offer reassurance to the carer that they are not entirely alone. The development of interdisciplinary primary care teams is welcome and a priority within the teams must now be to address the absence of a strong culture of case management, and critically this has to be done without the traditional overly-rigid professional boundaries and restrictive work practices. Short intensive interdisciplinary dementia case management courses need to be delivered in

### 'Guiding support for family carers'

significant numbers over the coming years to give expression to this stated priority of primary care. In doing so, a wide range of health and social care professionals will be suitably equipped to become 'case managers'

Flexible respite care, that meets the needs of both the person with dementia and insofar as is practicable, the needs of the primary Family Carer, is a priority. In home support must be at the centre of this provision.

We support the recommendation from the Creating Excellence report (p101) regarding the need to support family carers to continue to be involved in care, as their loved one moves to a residential/acute care setting.

Current structures appear at times to make it easier to access (arguably unnecessary) residential care than to access suitable home care support. This is dysfunctional, and we would hope that with the development of a standardised single assessment tool, that such practices will not continue in the future.

Protecting income supports for Family Carers is also considered to be a priority.

Overall, there is a need to ensure that actions emanating from any National Dementia Strategy complement those existing commitments in the recently published National Carers Strategy.

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