

# Living and dying with dementia in Northern Ireland:

## Barriers to care

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Executive Summary  
April 2015

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By 2020, the number of people in Northern Ireland aged over 75 is expected to increase by 40% and the number of people aged over 85 is expected to increase by 58%.

While more people living for longer is something to be celebrated, it is a fact that many in this older age group will also be living with multiple and complex health conditions or terminal illnesses, such as dementia. Here in Northern Ireland, there are estimated to be nearly 20,000 people living with dementia, only 64% of whom have been diagnosed.

To date much of the focus on dementia has been on living well with the condition. While this is important, the focus on quality of life and care must extend beyond diagnosis to the end of life for people with dementia. In Northern Ireland in 2013, 954 women and 451 men had their death attributed to dementia and this number is growing. For too long, the late stages of dementia have been the forgotten aspect of what has been referred to as a [‘silent epidemic’](#).

We need to build on the positive work which has been done over recent years in Northern Ireland to improve awareness of dementia and enable people to live the lives they want to, for longer, and to plan for the end of their lives.

We must ensure a stronger focus on dementia as a terminal condition and take action to ensure quality of care from diagnosis to the end of life.

This report, *Living and Dying with Dementia in Northern Ireland* by Marie Curie and the Alzheimer’s Society, draws together what we know about dementia from research into health and social care in Northern Ireland. It identifies barriers which prevent many people with dementia from accessing and receiving appropriate high quality care at the end of their lives.

The report identifies three overarching themes:

1. **Identification and planning.** A series of barriers, including the lack of timely diagnosis, has highlighted that people with dementia are not being appropriately identified for care they will need as their dementia progresses and as they near the end of their lives.
2. **Inequality of access.** People with dementia have less access to palliative and hospice care than people with other terminal illnesses. They may also experience discriminatory barriers to funding for care they need as a direct result of their dementia.
3. **Quality of care.** People with dementia receive poorer quality care than people with other terminal illnesses. Issues such as poor pain management and avoidable hospital admissions may arise from lack of understanding of dementia as a terminal illness.

The wider issues facing those who design deliver and commission health and social care services, include the changing demographic pressures, existing and growing health funding constraints and our enhanced understanding of the complex needs of people with dementia at the end of life. It is essential that we address these challenges in a radically different way and that the work begins now.

## Our challenge:

Our challenge is to improve care and support for people who are living and dying with dementia, as well as their families and carers. We need to build on the progress which has been made in Northern Ireland in transforming core services so that they can respond to the diverse needs of the growing number of people with dementia. This will require action across many different aspects of the health and social care system and will require the involvement of a number of organisations.

## **Moving Forward:**

We must start to remove the barriers that prevent many people with dementia in Northern Ireland from accessing and receiving the high quality end of life care they need. This must include support for health and social care professionals to provide this care.

Marie Curie and the Alzheimer's Society are committed to working with a range of partner organisations, including representatives from the statutory and voluntary sectors, to raise awareness and understanding of key aspects of dementia and end of life care and to address the barriers identified throughout the report.

## **Redressing the imbalance:**

Our ambition must be to achieve seamless end of life care for people with dementia, based on their individual needs, regardless of where they live in Northern Ireland. In doing so, we must recognise that dementia is a terminal condition and those living with it have very different needs and experiences to people with other terminal illnesses.

The challenge for society will be to ensure people with dementia are supported to live their lives as they want, for as long as possible, and to plan for a time when they may lack capacity to make their wishes known. As they approach the last weeks and months of their lives, they must be able to access the appropriate care and support they need.

To make this a reality we need to start redressing the imbalance now, and we all have a part to play.

## **[Read the full report.](#)**

**For more information**

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Marie Curie Cancer Care gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end.

[mariecurie.org.uk](http://mariecurie.org.uk)

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.

[alzheimers.org.uk](http://alzheimers.org.uk)

