Executive Summary
December 2014

Living and dying with dementia in England:

Barriers to care

Over the coming decades, the number of older people living in the UK is likely to rise considerably. By 2030, the proportion of the UK aged over 85 is set to double and as a result we are likely to see a significant increase in the number of people living and dying with dementia. To date much of the focus has been on living well with dementia, with little focus on the experiences of people with dementia nearing the end of their lives. For too long, the dying phase of dementia has 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 to improve awareness of dementia and enable people to live the lives they want to for longer. We must ensure a stronger focus on the inevitable conclusion of what is a progressive, terminal condition. Those with dementia will die (whether directly as a result of dementia or of another co-existing condition) and we must improve the care of people in the later stages of dementia.

This new report from Marie Curie and the Alzheimer's Society draws together what we know about dementia from research into health and social care services in England. It identifies those barriers which prevent many people with dementia from accessing and receiving appropriate high quality care at the end of their lives.

Alzheimer's Society
Leading the fight against dementia

Marie Curie Cancer Care

We identify three overarching themes and a series of barriers:

1) Identification and planning

- lack of timely and appropriate diagnosis
- poor recognition of dementia as a terminal condition
- failure to identify dementia as a cause of death
- ineffective advance care planning

2) Inequality of access

- to palliative care
- to hospice care
- to funding
- discrimination

3) Quality of care

- inconsistency in care standards in hospitals
- inappropriate hospital admissions
- lack of continuity of care
- poor pain management
- inappropriate interventions
- failure to adapt practice to reflect the different nature of dementia
- lack of support for carers

The wider challenges facing those who design, deliver and commission health and social care services, including our ageing society and ongoing financial pressures, mean that we can't simply continue to deliver services in exactly the same way that we have in the past.

The number of people who will live and die with dementia over the coming decades means that we have to do something radically different. If we are to meet this challenge, our work must begin now.

We need to:

Remove barriers

We must start to remove the barriers that prevent many people with dementia from accessing the high quality end of life care they need. Our challenge is to improve the care and support for people who are living and dying with dementia, as well as their families and carers. We must also reach those health and social care professionals who care for and support them.

Our ambition must be to achieve seamless person-centred end of life care for people with dementia, regardless of where they live, who cares for them and the other conditions they have. In doing so, we must recognise that dementia is a terminal condition and that people with dementia have very different needs and experiences to people with other terminal conditions.

Transform core services

Many of our responses to terminal illness and ultimately to death and dying have been shaped in response to cancer. The modern hospice movement, palliative care and even the criteria by which Continuing Healthcare (CHC) funding applications are considered have been shaped in response to the needs and experiences of people with different forms of cancer.

Our challenge over the next decade is to build on the progress which has been made in many areas of the country in transforming core services so that they can respond to the needs of people with conditions such as dementia. This will require action across many different aspects of health and social care and the involvement of a number of organisations. We must be ready to respond in different ways to the diverse needs of people with dementia.

Work in partnership

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

We will do this over the coming months by bringing together people with direct experiences of caring for someone with dementia at the end of life and those who plan, design and provide care and support. This will include representatives of national NHS organisations, national and local commissioners, a range of Royal Colleges, charities, social care providers and those with expertise in hospice and palliative care. Our task over the course of 2015 will be to identify the practical steps which will enable us to remove each of the barriers identified by this report. We will report back on progress and the practical steps which have been taken in December 2015.

Redressing the balance

Over the coming decades, a growing number of people will experience the different forms of dementia.

The challenge for society will be to ensure that these people are supported to live their lives as they want for as long as they can. And that, when they approach the last weeks and months of their lives, they are able to access the most appropriate care, advice and support.

To make this a reality we need to start redressing the balance now, and we must all play our part.

To download the full report, go to:

mariecurie.org.uk/dementiareport

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

Marie Curie
Cancer Care

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

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