



Department of
**Health, Social Services
and Public Safety**
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IMPROVING DEMENTIA SERVICES IN NORTHERN IRELAND

A Regional Strategy

November 2011

***An “easy read” version of the strategy is available from the Department’s
website***

Ministerial Foreword

I am pleased to publish this document, *Improving Dementia Services in Northern Ireland – A Regional Strategy*. Drawing on best practice here and elsewhere, the strategy makes recommendations aimed at improving the services and support arrangements currently available for people with dementia, their families and their carers.

We are becoming increasingly aware that the ageing of the population throughout the developed world will lead to a continuing increase in numbers of people with dementia. The most recent expert views on the prevalence in Northern Ireland indicate that the number of cases may be as high as 18-19,000. It is thought that this figure could rise to around 60,000 by 2051. The scale of the challenge makes it vital that we re-design the services provided now and start to work differently to support people with dementia and their families.

Providing care for people with dementia already poses challenges for service providers, whether in the statutory or independent sectors. The increasing numbers of people with dementia will bring further pressure on care and support services and on those who provide informal care. It is clear that the human cost for people and their families living with dementia is huge and we must recognise that carers must also be cared for.

The views of those living with dementia and their carers have been vital in the development of this strategy. The strategy recognises the need to support the person and their carers so that, as far as possible, the person can remain in their own home environment and maintain their independence. I am however aware that it will not be possible for everyone to be supported in their own home. Where this is not possible, we want to ensure that everyone is supported in the environment that is right for their needs.

The strategy addresses a wide range of issues and includes an action plan to improve and redesign services, with timescales and an identified lead organisation for each action.

Edwin Poots MLA

Minister for Health, Social Services & Public Safety

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Executive summary

It is estimated that at present in Northern Ireland there are 19,000 people living with dementia; fewer than 1000 of these people are under 65. As the population of Northern Ireland ages, dementia will increasingly be a major public health and societal issue, with numbers of people with dementia rising to 23,000 by 2017 and around 60,000 by 2051. The cost to society is also likely to increase dramatically.

The dementia strategy will attempt to reduce the risk or delay the onset of dementia in the population; it has been estimated that delaying the onset of dementia by five years could halve its prevalence. Everyone needs to know that there are things that can be done to reduce the risk of dementia and to be aware of possible signs and symptoms of dementia.

The strategy and the values and principles which underpin it have been informed by the views of people with dementia and their families. A key message from them is that people with dementia should be supported to live with dignity and without stigma. There needs to be better awareness of dementia - among the general population, those who provide services to the public and, in particular, those who provide health and care services. The knowledge and skills of the staff involved in caring for people with dementia – whether in services specifically designed for people with dementia or in more general services – are a key element in improving services. Action on staff training and development is included in the action plan. The majority of care is provided by family and other informal carers, who in turn need support in their role.

People need to be encouraged to seek help as soon as possible. Early diagnosis allows people to receive treatment, care and support. Once diagnosed, people can stay independent for as long as possible, if they are given the right support, and they can plan for the future.

Dementia is a progressive disease and appropriate care and treatment will be different at each stage depending on the needs of the individual and their family. Care must promote and preserve independence and maintain the preferred patterns of daily living and links with family and friends.

For as long as possible people should be supported to remain in their own homes. Almost half of people with dementia in NI are in care homes, however. On any day another sizeable proportion are in acute hospitals, often staying for longer in hospital than other people. We need to ensure that those in care homes or in hospital need to be there and that they receive appropriate care in these settings.

New mental capacity and mental health legislation being developed will include powers and protections relating to substitute decision making for those who are unable to make their own decisions, including people with dementia.

Research on dementia is needed in the three main areas - *Cause, Cure and Care*. Dementia's world-wide impact calls for a co-ordinated approach to research, pooling

talents and resources. Northern Ireland researchers and professionals need to collaborate with others to maximise impact of research funding and expertise.

Overview of the Document

Sections 1 and 2 of this document outline why dementia is an important issue for individuals, families and for society, given the likely increase in the numbers of people affected and the pressure on public services and the cost to society.

Section 3 examines how the risk of developing dementia might be reduced or its onset delayed by lifestyle choices that reduce risk factors such as high blood pressure and smoking even though other risk factors cannot be modified.

Sections 4 and 5 highlight what people with dementia have told us is important to them and how support should be designed with that in mind.

Sections 6 and 7 look at how to raise awareness of dementia, how to encourage people to seek help as early as possible and how to ensure that people who present with symptoms are properly assessed and supported.

Sections 8-10 examine ways to improve the wide range of services used by people with dementia in order to promote their independence and quality of life.

Section 11 looks at the needs of family and friends who provide informal care.

Section 12 outlines the proposals for new legislation on mental capacity and mental health, to protect those who lack the capacity to make decisions for themselves.

Section 13 highlights the importance of research in this area and considers how Northern Ireland researchers can contribute to this world-wide challenge.

Section 14 sets out how the strategy will be taken forward, recognising the links with other strategies. It considers the cost associated with the development of dementia services and the potential for reallocation of resources through service redesign.

An Action Plan at Section 15 summarises the actions, indicating which organisation will have lead responsibility and the timescale for completion.

SECTION 1: WHY DEMENTIA IS IMPORTANT

Aim and Scope of the Dementia Strategy

1.1 Dementia is the term used to describe a group of conditions that affect the brain and cause a progressive decline in the ability to think, remember and learn¹. Dementia affects people differently and can have a significant impact on the life of the individual, their family members and carers. As the population of Northern Ireland ages, dementia will increasingly become a major public health and societal issue.

1.2 Our dementia strategy will:-

- promote a greater understanding of how dementia impacts on the lives of individuals, and how people can be supported to live well, with dignity and as valued members of our society;
- raise public awareness of dementia and how people can take some measures to reduce the risk of developing dementia or potentially delay its onset;
- encourage sharing of information on dementia to allow individuals, families and carers to make informed decisions, maximise independence and enhance daily living;
- respond to the voice of people with dementia and their carers, and promote access to earlier diagnosis and multidisciplinary assessment and support through further development of health and social care commissioning, thus placing the person with dementia, their families and carers at the centre of the care planning processes; and

¹ National Framework for Action on Dementia 2006-2010; NSW Department of Health on behalf of Australian Health Ministers' Conference (2006)

- promote partnership working that recognises the pivotal role of carers and integrates the activity and skills of those who work in the statutory, community, voluntary and independent sectors.

1.3. The following paragraphs highlight the strategic context for the development of this strategy, recognising that evidence on what is effective for the care of dementia improves over time and that there are published examples of dementia good practice at international, national and local levels. This section finishes by describing in more detail the types of dementia and how this condition impacts on the lives of individuals, families and carers.

Strategic Context

1.4 The overarching strategic context for this work is the Executive's Programme for Government priority of promoting tolerance, inclusion, health and well-being. *Ageing in an Inclusive Society*² aims to promote the social inclusion of older people and create an enabling environment, which gives older people choice and control over the services that influence their lives. A Commissioner for Older People has been established in law to provide a 'strong independent voice' for older people. A Commissioner has been appointed in 2011 to:

- stand up for and speak for older people;
- help shape government policy in the interests of older people;
- raise public awareness by publishing research on issues affecting the lives of older people;
- challenge discrimination against older people and promote their participation in public life;
- encourage best practice in the treatment of older people;
- investigate and resolve complaints on their behalf;
- commission mediation services to help resolve difficult disputes;
- if necessary, take legal cases on behalf of older people or assist older people with their own legal cases.

² *Ageing in an Inclusive Society*; Office of the First Minister and deputy First Minister 2005

- 1.5 The last formal review of the Department of Health, Social Services and Public Safety (DHSSPS) policy on dementia was undertaken in 1994³. Since then a number of reports and strategy documents on fresh approaches to dementia care and support have been written with much common ground in terms of issues addressed.
- 1.6 The Bamford review's report 'Living Fuller Lives'⁴ made recommendations in relation to services for people with dementia. These recommendations were intended to improve the identification, treatment and care of people with dementia and to give greater support to their carers. The Bamford review recommended integrated working across primary, secondary and community care to maximise the beneficial effect for people with dementia and their carers. The review also recommended the development of public education programmes to promote good mental health and facilitate prevention.
- 1.7 We can share learning on dementia care at international level, for example, in Canada, America, Europe and Australia. In England a national strategy "Living Well with Dementia"⁵ was published in February 2009. This strategy provided a framework within which local services could deliver quality improvements to dementia services and address health inequalities relating to dementia. In addition, the National Institute for Health and Clinical Excellence (NICE) has issued two sets of guidance pertaining to dementia care^{6,7}. These have recently been endorsed as applicable in NI.
- 1.8 The Scottish Government has also published a dementia strategy⁸. In addition, the Scottish Intercollegiate Guidelines Network produced guidance on the management of dementia⁹.

³ Dementia in Northern Ireland – Report of the Dementia Policy Scrutiny; DHSS 1994

⁴ Living Fuller Lives; Bamford Review of Mental Health and Learning Disability (Northern Ireland) 2007

⁵ Living Well with Dementia: A National Dementia Strategy; Department of Health 2009

⁶ Dementia: supporting people with dementia and their carers in health and social care; Clinical guideline 42, NICE 2006 (Amended March 2011)

⁷ Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease; Technology appraisal guidance 217, NICE 2011

⁸ Scotland's National Dementia Strategy: Scottish Government 2010

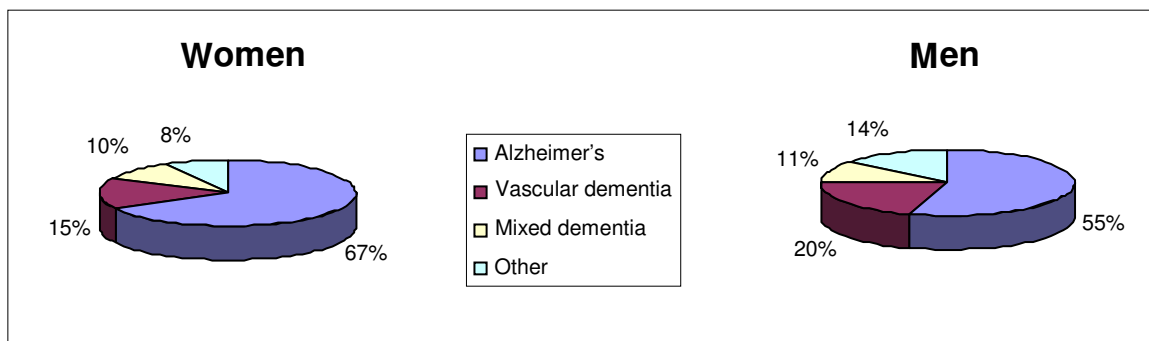
- 1.9 Clear strategic direction is essential for Northern Ireland, in order to improve services for people with dementia and for their carers and support them. In addition, we need to prepare for the challenges that lie ahead with anticipated increases in the numbers of people with dementia in the future.

Dementia – the Different Types and their Impact

- 1.10 There are many different types of dementia, some of which are relatively rare. The most common cause of dementia is Alzheimer’s disease which accounts for over 50% of dementia. The next most common form is vascular dementia, which is diagnosed in about 20% of cases. Mixed dementia where there is both Alzheimer’s disease and vascular factors is also common.
- 1.11 Other types of dementia include frontal lobe dementia, Pick’s disease, Lewy Body disease, and alcohol related dementia. People may also develop dementia as part of another condition including Parkinson’s disease, Creutzfeldt-Jacob disease, HIV/AIDs and Huntington’s disease. People with Down’s Syndrome are affected by dementia at an earlier age than the rest of the population, so it is more prevalent in those people.

⁹ Management of patients with dementia: A national clinical guideline; Scottish Intercollegiate Guidelines Network 2006

Chart 1: Prevalence of types of dementia in women and men (all ages) in UK



Source: Dementia UK report¹⁰

1.12 When a person has dementia the nerve cells in the brain are damaged and die faster than normal. When the nerve cells die they cannot be replaced.

1.13 The symptoms of dementia may include:-

- problems with memory, reasoning and judgement;
- disorientation;
- language and communication difficulties;
- changes in mood, behaviour, or personality;
- wandering behaviours; and
- hallucinations and delusions.

1.14 These symptoms are not exclusive to dementia; other common causes of these symptoms include depression, stress, delirium and the side effects of some medications. Therefore, an early and accurate diagnosis is important to ensure appropriate intervention and support which is tailored to individual needs. Although dementia is a progressive condition, a lot can be done to help the person with dementia to live well. Further information on the progression of dementia and what can be done, including how the use of aids, adaptations and technology can help people with dementia, is given in Appendices 2 and 3.

¹⁰ Dementia UK; LSE, King's College London and Alzheimer's Society 2007

Summary

- 1.15 This section focuses on the impact of dementia on the individual, their family and carers. The next section describes the prevalence of dementia and why it is a growing public health and societal issue which must be recognised and addressed.

SECTION 2 – THE IMPACT OF DEMENTIA ON SOCIETY

Facts and Figures

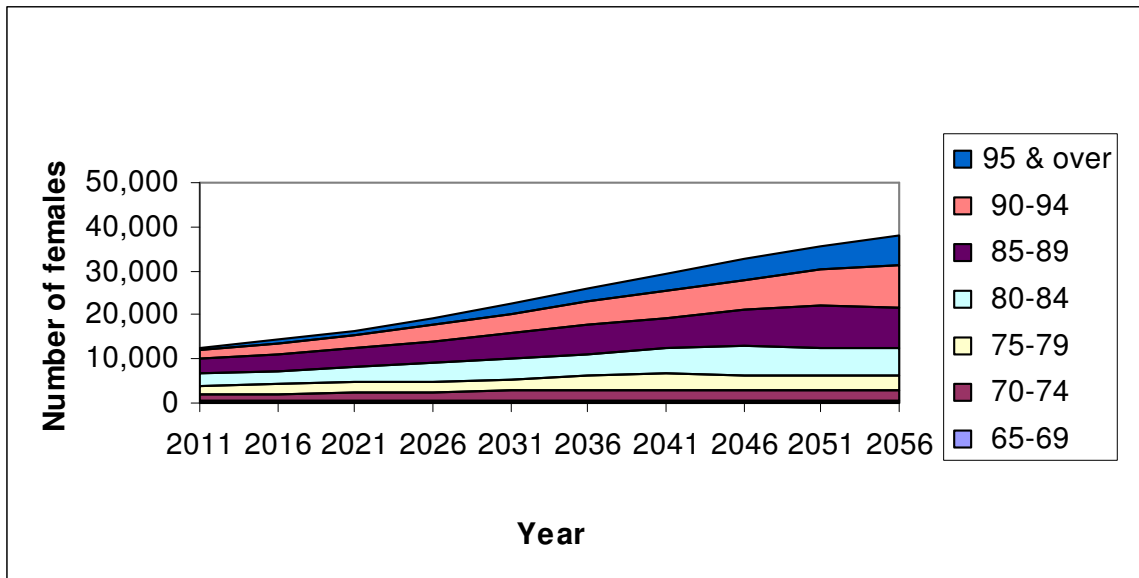
- 2.1 Dementia mostly affects people over the age of 70 and is uncommon in people under the age of 60 but it can appear, though rarely, in people in their 40s or younger. Research shows that, after 65, the prevalence of dementia doubles with each additional five years of life.
- 2.2 Over the next 40 years, as our society ages, dementia will become more common in Northern Ireland. Providing support and care for people with dementia already poses challenges for families and for service providers, whether in the statutory or independent sectors. Meeting the demands likely to arise from the projected increase in people -aged 65 and over - will compound these problems and there are significant implications, both personal and public.
- 2.3 At present, it is estimated that in Northern Ireland there are 19,000 people living with dementia; fewer than 1000 of these people have early onset dementia (ie are under 65 years of age)¹¹.
- 2.4 An ageing population in Northern Ireland could see the numbers of people diagnosed with dementia rising from the current estimate of 19,000 to 23,000 by 2017 and around 60,000 by 2051.
- 2.5 The average life expectancy for a woman in Northern Ireland is currently 81 years and for a man is 76 years¹². As dementia occurs more frequently in the older age groups and as women live longer than men, then women have a higher prevalence of dementia than men. This is reflected in population

¹¹ European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) study from Hofman A. et al. The prevalence of dementia in Europe; a collaborative study of 1980-1990 findings, International Journal of Epidemiology 1991

¹² Health and Social Care Inequalities Monitoring System: Life Expectancy Decomposition – An overview of changes in Northern Ireland life expectancy 2001-03 to 2006-08, DHSSPS 2011

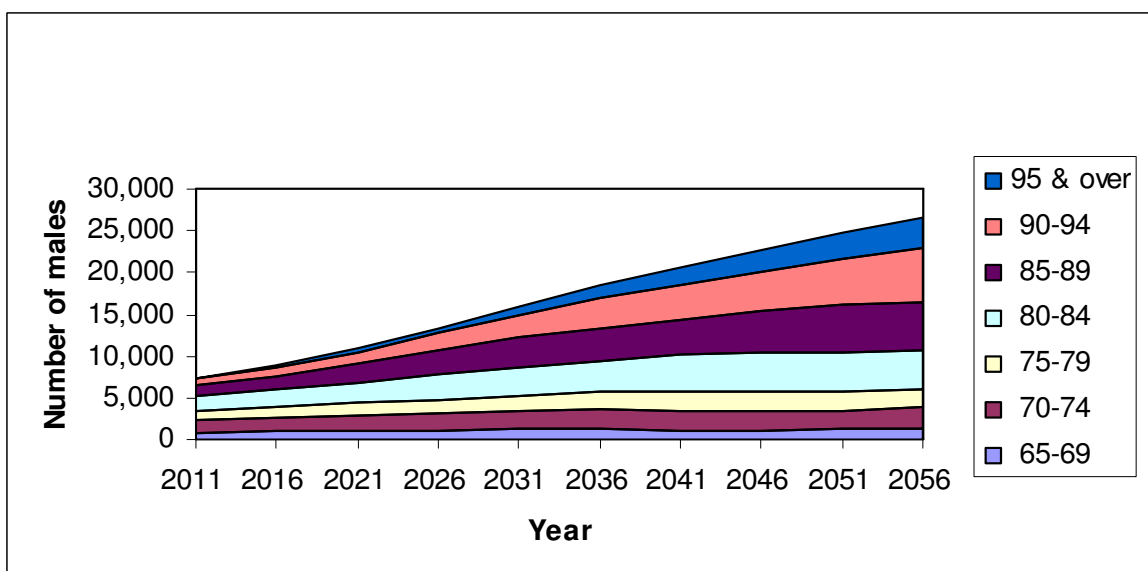
projections where it is estimated that by 2056 there will be 38,000 women and 26,500 men affected by dementia.

Chart 2: Projected number of women with dementia in Northern Ireland



Source: EURODEM Prevalence rates applied to NI population projections

Chart 3: Projected number of men with dementia in Northern Ireland



Source: EURODEM Prevalence rates applied to NI population projections

- 2.6 If the onset of dementia could be prevented or delayed, it would have very important implications for the numbers of people affected, for the services that would be required and for society, as substantial additional costs accrue with an increased prevalence of the condition.

The Cost of Dementia Care

- 2.7 The cost of dementia care is substantial, both to the public purse and to those living with dementia and their families. The Alzheimer's Society report¹³ estimated the annual average cost of care for someone with dementia to range from £16,700 (2005/06 prices) for someone with mild dementia living in the community to £37,500 for someone with severe dementia living in the community. The average cost for someone in supported accommodation, including care homes, was estimated at £31,300. All of the costs quoted include informal care costs – the cost of the time informal carers spent on providing care -, health and social care costs and supported accommodation costs for those receiving this form of support.
- 2.8 Applying these to the Northern Ireland estimates of those with dementia and assuming the same distribution as the UK as a whole for the proportions with mild, moderate and severe dementia and for the proportion living in supported accommodation gives total NI costs (at 2005/06 prices) of just over £400m, which includes £150m of informal care costs.

¹³ Dementia UK; LSE, King's College London and Alzheimer's Society 2007

Table 1: Estimated cost of dementia care in Northern Ireland

	£m (2005/06 prices)	Uplifted to 2011/12 prices £m
Informal care costs	149	175
Health and social care costs	93	109
Supported accommodation costs	163	192
TOTAL	405	476

Source: Dementia UK report for 2005/06 costs

- 2.9 The precise cost of health and social care services provided for people with dementia in Northern Ireland cannot be obtained because:
- people with dementia often have other health and social care needs which are also being met; and
 - people with dementia often use services which are not earmarked as being specifically for people with dementia, for example, domiciliary care.
- 2.10 The Bamford review of mental health and learning disability estimated the health and social care costs of dementia services to be over £200m (2004/05 prices) by assuming the proportions of various key elements of services for older people that would be attributed to the care of people with dementia. The main elements of these costs are shown below.

Table 2: Bamford review's estimated cost of dementia care in Northern Ireland (2004/05 prices)

	£m
Domiciliary care (assuming 50% of all elderly care costs attributed to dementia care)	52
EMI nursing homes	43
EMI residential homes	19
Other elderly and mental health residential homes (assuming 70% attributed to dementia)	43

care)	
Psychogeriatric hospital service	28
Social workers in elderly care (assuming 80% attributed to dementia care)	15
Other elderly and mental health care and treatment	12
Total	212

Source: Bamford review of mental health and learning disability – working papers

2.11 This estimate would equate to a cost of about £250m at 2011/12 prices. It must also be recognised that this cost relates only to health and social care costs and excludes contributions made by people in care homes who are meeting some or all of their care costs.

2.12 As the Northern Ireland population ages, health and social care expenditure on services for people with dementia could be expected to double within 20 years.

Summary

2.13 This section highlights the impact of an ageing society in Northern Ireland and emphasises that the prevalence of dementia will increase substantially over the coming years. This will have a major impact not only on individuals and families but also on service provision and on society as a whole where costs associated with caring for and supporting those living with dementia will rise substantially.

2.14 The next section highlights what we, as a society, might be able to do to prevent or delay the onset of dementia by promoting healthier lifestyles and by reducing risk of cardiovascular disease.

SECTION 3: Reducing the Risk or Delaying the Onset of Dementia

3.1 Some risk factors associated with certain forms of dementia are modifiable, and where possible, attempts should be made to prevent or delay the onset of dementia in the population. Even delaying the onset of dementia in the population would effectively be a preventative strategy as it has been estimated that delaying the onset of dementia by five years could halve its prevalence i.e. half the number of people with dementia at a point in time¹⁴. While there is currently no definitive evidence of cause and effect in the prevention of dementia, the balance of risks points strongly to the value of taking a preventative approach.

What is Prevention?

3.2 Prevention of any condition can be considered under three sub-headings:

Primary prevention involves addressing the determinants of health (eg lifestyle and other risk factors) to prevent the onset of disease;

Secondary prevention involves early detection of disease, followed by appropriate intervention, such as health promotion and /or treatment in an attempt to control the disease and prevent further deterioration in health; and

Tertiary prevention aims to reduce the impact of the disease and promote quality of life through active rehabilitation and enabling people to live well with the disease.

What are the Risk Factors for Dementia?

3.3 In order to consider ways in which the risk of dementia might be reduced or delayed it is first necessary to examine the risk factors which may increase

¹⁴ Jorm, AF, Korten, AE & Henderson, AS (1987) The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica*, 76, 465-479.

the likelihood of developing dementia. Risk factors for any condition fall into two groups:

- i) risk factors that cannot be modified e.g. age; and
- ii) risk factors that are potentially modifiable i.e. it is possible for action to be taken which may reduce the risk of developing disease.

3.4 Much remains unknown about factors that place individuals at risk or help protect against dementia. It is not known which of the risk factors listed below are the most important and account for the largest number of cases. In many cases it is also not known whether intervening to modify these risk factors has any impact on preventing dementia and more research is needed on this issue. Some risk factors are common to most types of dementia while others are specific to particular types of dementia.

Risk factors which cannot be modified

3.5 Risk factors which cannot be modified are:

Age - advancing age is the biggest risk factor for dementia, although some of the rarer forms of dementia have their onset in mid-life.

Gender - there are higher rates of Alzheimer's Dementia in women than men. Both the incidence (ie rate of onset of new cases) and prevalence (all cases at a point in time) are higher among women. Rates of vascular dementia are higher among men although women catch up at older ages.

Learning Disability - the ageing process for people with learning disability begins much earlier. People with Down's syndrome have high rates of Alzheimer's type dementia.

Genetic Factors - A number of genetic mutations have been identified which are associated with an increased risk of dementia.

Risk factors that could be modified

3.6 Some risk factors are modifiable and will improve our population health. The following risk factors could prevent or delay the onset of dementia:

- **Smoking** - Smoking is a risk factor for all types of dementia including Alzheimer's disease. It is also a risk factor for the development of heart disease and stroke which lead to an increased risk of vascular dementia.
- **Alcohol** - Excessive alcohol consumption is a risk factor for the development of dementia. Drinking alcohol within the recommended safe limits is unlikely to increase the risk of dementia.
- **Obesity** - There is some evidence that obesity in mid-life is associated with an increased risk of dementia in later life- particularly Alzheimer's Dementia. Obesity is also a risk factor for diabetes which in turn increases the risk of heart disease and stroke and therefore also vascular dementia.
- **Raised blood pressure** - raised blood pressure in mid-life has been shown to be a risk factor for the development of both vascular dementia and Alzheimer's disease. It is also a risk factor for the development of heart disease and stroke which themselves increase the risk of dementia. Treatment of high blood pressure has been shown to reduce the risk of heart disease and stroke but it is not yet clear whether treatment of blood pressure reduces the risk of dementia and further research is needed.
- **Raised cholesterol** - this is known to be a risk factor for heart disease and stroke. It is also associated with Alzheimer's disease but it is not yet clear whether reducing cholesterol reduces the risk of dementia.
- **Raised homocysteine levels** - there is some evidence that raised homocysteine levels in the blood and low levels of folate may be associated with heart disease, stroke and an increased risk of dementia.

However research to date has not shown any benefit of treating raised homocysteine levels in terms of preventing or delaying dementia.

- **Depression** - there appears to be an increased risk of dementia in those with a history of depression although the relationship between the two is not clear.
- **Hormone Replacement Therapy** - it was previously thought that HRT may protect against dementia but more recent studies have shown that HRT may actually increase the risk of dementia and it should therefore not be used for the sole purpose of reducing the risk of dementia.
- **Head Injury** - head injury severe enough to cause loss of consciousness has been found to be associated with an increased risk of dementia but this may only hold true for males. The evidence is not strong in this area but avoidance of serious head injury is desirable for many reasons.
- **Chronic occupational exposure to toxic agents** - research regarding links between exposure to a range of occupational agents and the risk of developing Alzheimer's disease has been carried out but findings are generally inconsistent. A small number of studies however point towards an association between exposure to pesticides and risk of Alzheimer's disease. Firm recommendations in this area cannot be made, but research relating to exposure to exogenous agents should be kept under review.
- **Lower levels of educational attainment** - there is some evidence that lower educational attainment may be associated with the subsequent development of dementia. However, it is not clear whether there is a true increase in this group or whether the condition simply becomes more apparent at an earlier stage in this group.

Factors which may protect against the development of dementia

3.7 There are a number of risk factors which protect against the development of dementia. These include:-

- **Participation in physical activity** - participation in physical activity for 20-30 minutes twice a week in mid-life has been shown to be associated with a lower risk of dementia in later life. Although there is not enough evidence to recommend physical activity specifically for reducing the risk of dementia, clearly it has other benefits in terms of maintaining general health.
- **Eating a healthy diet** - studies have shown that a Mediterranean style diet and consumption of fish is associated with a reduced risk of Alzheimer's disease. Although the evidence linking diet with dementia is very limited a healthy diet rich in fruit and vegetables and low in saturated fat is advisable for the general population in terms of maintenance of general health and is particularly important for those who have existing heart disease or raised cholesterol.
- **Participation in mentally challenging leisure activities** – participation in activities such as board games, reading, playing a musical instrument, dancing are associated with lower risk of developing dementia, although further research is ongoing in this area and firm recommendations cannot yet be made.

3.8 Action is already being taken to address many of these risk factors within the population through work to promote health lifestyles in support of the Investing for Health¹⁵, Cardiovascular Services Framework, Mental Health Promotion Strategy, Quality and Outcomes Framework (QOF) in Primary Care and other strategies.

¹⁵ Investing for Health: DHSSPS 2002

NICE Guidelines

3.9 Based on the limited evidence available the NICE/ SCIE guideline¹⁶ makes the following recommendations:

- **Screening for dementia**

General population screening for dementia should not be undertaken.

- **Primary Prevention**

In middle age and older people, vascular and other modifiable risk factors for dementia (eg smoking, excessive alcohol intake, obesity, diabetes, hypertension, and raised cholesterol) should be reviewed and if appropriate treated.

There is no role for prescribing statins, hormone replacement therapy, non-steroidal anti-inflammatory drugs or antioxidants for the primary prevention of dementia.

- **Genetic issues**

Healthcare professionals working with people likely to have a genetic cause for their dementia (generally those with specific young-onset dementias) should offer to refer them and their unaffected relatives for genetic counselling. Regional genetic services should provide genetic counselling to people who are likely to have a genetic cause for their dementia and their unaffected relatives. If a genetic cause for dementia is not suspected, including late-onset dementia, genotyping should not be undertaken for clinical purposes.

- **Secondary prevention**

For the secondary prevention of dementia, vascular and other modifiable risk factors (for example, smoking, excessive alcohol

¹⁶ Dementia: supporting people with dementia and their carers in health and social care; Clinical guideline 42, NICE 2006 (Amended March 2011)

consumption, obesity, diabetes, hypertension and raised cholesterol) should be reviewed in people with dementia, and if appropriate, treated.

Way Forward in terms of Risk Reduction

- 3.10 Since the evidence is not strong in relation to risk reduction, it is not appropriate at this stage to develop large scale education strategies for the general public regarding prevention of dementia. Many of the risk factors that appear important and initiatives that seem promising are already being addressed as part of existing strategies.
- 3.11 Many people at risk of dementia are already receiving care and treatment for other conditions such as coronary heart disease, stroke, high blood pressure, diabetes, depression or learning disability. This contact provides an opportunity for health and care staff to promote healthy lifestyles and to pick up early signs of dementia. There are existing targets for GPs in relation to management of patients with these long term conditions.

Actions

General population

The Public Health Agency will continue to promote healthy lifestyles and avoidance of risk factors to the general population for the prevention of heart disease, stroke, mental illness etc.

In addition the Public Health Agency will consider developing initiatives that may reduce serious head injuries.

Middle aged and older people

Primary care professionals will opportunistically offer lifestyle advice and if appropriate review and treat vascular and other modifiable risk factors in accordance with existing guidelines as part of a primary prevention strategy.

People with existing disease which places them at risk of dementia

Primary care professionals will be alert to the increased risk of dementia for all patients on the cardiovascular, stroke, hypertension, diabetes, obesity, depression and learning disability registers. Patients on these registers will be reviewed and offered lifestyle advice and management of risk factors as appropriate, and encouraged to seek help early if they develop possible signs of dementia.

Consideration will be given to the addition of primary prevention targets for dementia to the Quality and Outcomes Framework.

Patients who have a diagnosis of dementia

As part of the ongoing care of people with dementia (or presenting with possible signs) primary care professionals (in collaboration with carers where appropriate) will review and if appropriate treat vascular and other modifiable risk factors. Consideration will be given to the further development of secondary prevention targets to the Dementia Indicator within QOF.

Clear protocols will be developed for primary and secondary care professionals for any referral to genetic services for patients likely to have a genetic basis to their dementia and their unaffected relatives.

Summary

3.12 This section focuses on the primary prevention of dementia and touches on modifying risk factors in secondary prevention. In middle and older age, vascular and other modifiable risk factors including smoking, excessive alcohol intake, obesity, diabetes hypertension, raised cholesterol should be reviewed and, if appropriate, treated. Essentially what is good for general health and cardiovascular health is also likely to be good for dementia. A number of action points are identified which link to other strategies and frameworks. These actions are designed to raise awareness of modifiable risk factors and the need to treat when appropriate.

3.13 The next sections will focus on people with a diagnosis (or possible diagnosis) of dementia. Section 4 will highlight what matters to people and their families living with dementia. Section 7 deals in more detail with early detection and intervention and Section 8 will focus on tertiary prevention or rehabilitation and maintaining a high quality of life.

Section 4: What Matters to People with Dementia and Their Families

4.1 The views of people with dementia and their families have been sought and considered to ensure that this strategy is relevant to them. Recognising the challenges involved in obtaining these views in a meaningful way that does not add stress to those taking part, the Alzheimer's Society, funded by DHSSPS, carried out research to help inform the strategy.

Key Recommendations from Listening Well Report

4.2 The full report on this research, entitled *Listening Well*, has been published by the Alzheimer's Society¹⁷. The key recommendations that emerged from the work are:

Raising awareness of dementia

- Training should be provided to both generic and specialist HSC staff to improve awareness and understanding of dementia;
- Organisations working in the field of dementia should engage with local and national media to encourage better understanding of dementia and support those with dementia to speak publically about their lives.

Improving the experience of receiving a diagnosis of dementia

- Ensure services are in place to enable early assessment and diagnosis of dementia;
- Appropriate training should be provided on how to communicate a diagnosis;
- Information should be provided to people diagnosed with dementia detailing available support;

¹⁷Listening Well; Alzheimers' Society, 2009

- Information on a person's diagnosis should be shared amongst relevant professionals involved in a person's care;
- The needs of the person with dementia, and their family/carers, should be taken into account at all stages of diagnosis and support.

Improving access to information, support and advocacy after diagnosis

- Every person diagnosed with dementia should be allocated a key worker;
- Ensure there is a more comprehensive and consistent system in place for the provision of practical advice, information and support to people with dementia and their families/carers;
- Enable people with dementia to make their own decisions while they are able to do so;
- Ensure consistency in prescribing policies and information on prescribing;
- Independent information, support, and advocacy should be offered at the point of diagnosis;
- Family and carers should be provided with training and support.

Further research

- Research should be commissioned to further look at people's experiences of assessment and diagnosis, as well as conducting research with seldom heard groups in order to gain a fuller understanding of their perspectives and needs.

Bamford Consultation with Service Users and Carers

4.3 The Bamford review had carried out consultation with service users and carers for Living Fuller Lives, but some service users and carers and organisations representing them felt that the group discussions which were

used in the consultative process were not conducive to encouraging and reflecting adequately on the responses from people with dementia themselves. The key recommendations in paragraph 4.2, however, have resonance with the views of service users and carers obtained by the Bamford review¹⁸.

4.4 The Bamford review consultation with service users and their carers highlighted issues as follows:

- people need access to a range of appropriate treatments, therapies and activities in keeping with their needs and the stage of their condition;
- people with dementia should be enabled to stay at home if at all possible, facilitated by intensive support mechanisms and innovative housing responses involving assistive technologies and well integrated into local communities;
- increased access is needed to specialist day care and specialist dementia units;
- people with dementia are often not afforded the time, respect and level of care they deserve, including access to appropriate treatment for physical illnesses;
- staff training on dementia is needed at all levels;
- continuity of care staff needs to be supported through appropriate recruitment and retention practices;
- physical environments need to be in keeping with the requirements of the person with dementia;
- provision for younger people with dementia and for people with a learning disability and dementia requires joined up, collaborative approaches.

Rights of People with Dementia

4.5 Building on these findings on what matters to people living with dementia, a number of values and principles have been identified which will inform future service redesign and development. These values and principles aim to

¹⁸ Consultation Report – Older People - Dementia and mental health issues; The Rural College 2005

uphold the rights of people with dementia and promote their social inclusion. This is in keeping with the UN Convention on the Rights of Persons with Disability which seeks to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.

Values and Principles for Dementia Services

4.6 The following values and principles have been considered as key to guiding the future development of services for people with dementia and the people who care for them. These values and principles reflect the views of a range of stakeholders, including people with dementia and their families and carers.

Dignity & Respect

People with dementia have a right to the highest attainable standard of health and well-being and to be supported to live with dignity and without stigma in a society that values them.

Autonomy

People with dementia will be assumed to have capacity to make decisions unless the contrary is established.

All practicable steps will be taken to help the person with dementia to make a decision for him or herself before they will be treated as unable to do so.

People with dementia and their carers will be:

- treated as individuals;
- supported to maximise their independence, their health and wellbeing;
- asked about their choices, needs and preferences for care, treatment and activities of daily life and have these respected and taken into consideration in decisions about treatment and care;

- included in the planning, design and delivery of services;
- provided with accurate and timely information to support them in making decisions and choices about their life and future; and
- supported to make informed decisions about risks and benefits.

Justice & Equality

People with dementia are protected under the law to ensure their human rights, their physical, social, emotional and sexual health and well-being and their property rights are upheld.

People with dementia, regardless of culture, gender, sexuality, marital status, age, religion or disability have an equal right to services which promote their health, dignity and independence.

Safe, Effective, Person Centred Care

Flexible and responsive person centred services for people with dementia will ensure just and equitable provision from diagnosis of the condition to the end of life.

Services will engage in continuous improvement based on research and best practice, to enhance the lived experience of people with dementia at all stages of their condition and ensure best use of available resources.

The physical environment in which care, treatment and support is provided will be designed to maximise the abilities of people with dementia to ensure they remain included, enabled and as independent as possible.

Care for Carers

Carers will be supported as essential partners in the care of people with dementia.

