



Department of
**Health, Social Services
and Public Safety**
www.dhsspsni.gov.uk

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

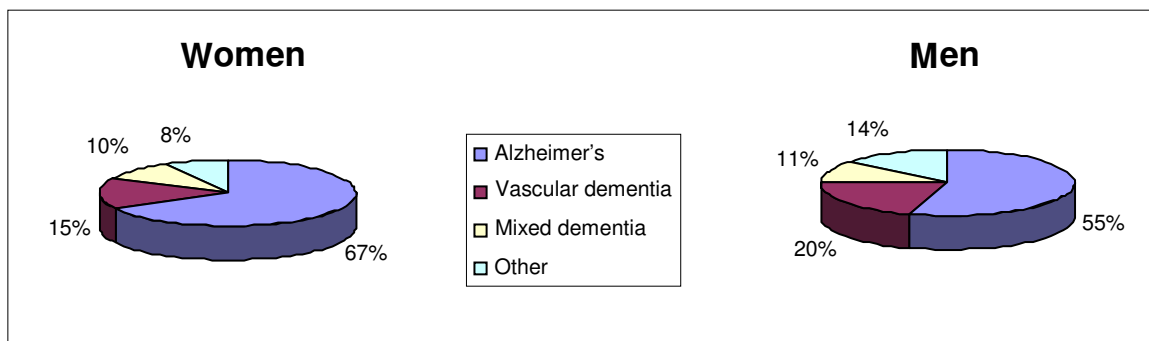
- 1.9 Clear strategic direction is essential for Northern Ireland, in order to improve services for people with dementia and for their carers and support them. In addition, we need to prepare for the challenges that lie ahead with anticipated increases in the numbers of people with dementia in the future.

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

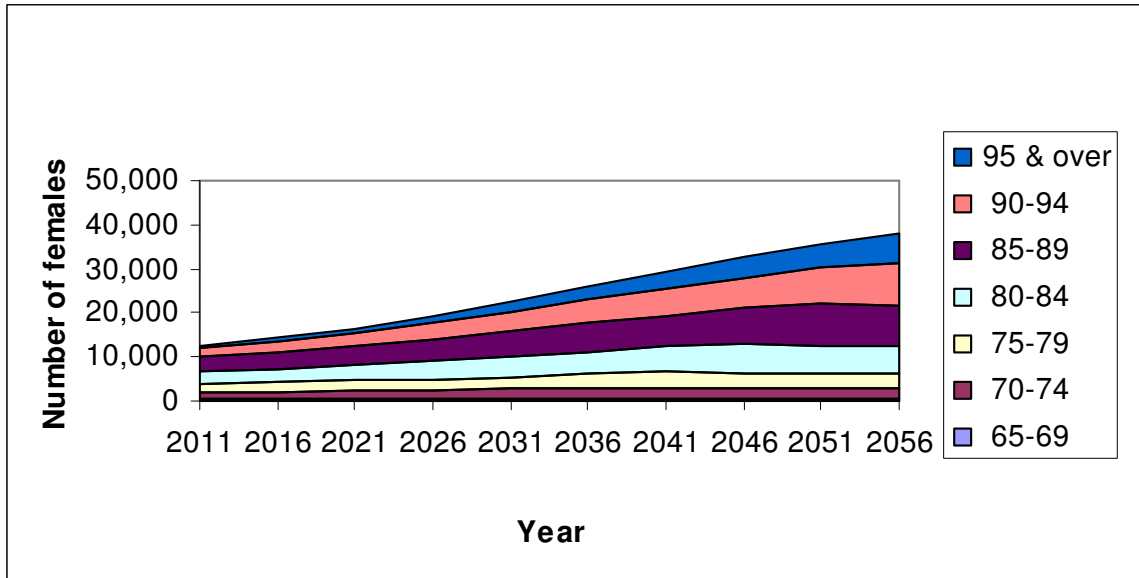
- 2.1 Dementia mostly affects people over the age of 70 and is uncommon in people under the age of 60 but it can appear, though rarely, in people in their 40s or younger. Research shows that, after 65, the prevalence of dementia doubles with each additional five years of life.
- 2.2 Over the next 40 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

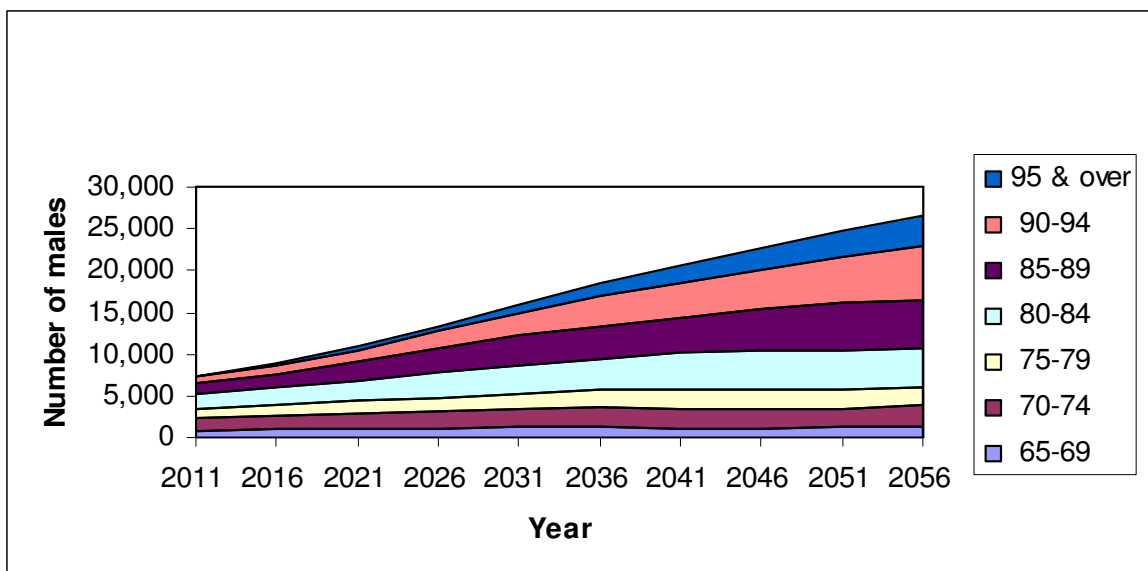
projections where it is estimated that by 2056 there will be 38,000 women and 26,500 men affected by dementia.

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.

Carers have a legal right to have their needs assessed

Skills for Staff

Professionals, care staff and volunteers will be required to demonstrate best practice commensurate with their role in all aspects of dementia care.

Professionals, care staff and volunteers will have access to information, training and education about all aspects of dementia care based on research and best practice.

Professionals, care staff and volunteers caring for people with dementia are of equal value with those working in other long term and chronic care specialties.

Summary

4.7 This section highlights the outcome of the “Listening Well” exercise which has documented what matters to people living with dementia and their families. Following this, values and principles have been developed which will be at the heart of dementia services redesign and development. These, together with those issues that have been identified by service users and their carers as important to them, have been incorporated into the next sections on:

- The model for supporting people with dementia – Section 5
- Raising awareness of dementia - Section 6
- Initial Assessment and Diagnosis – Section 7
- Supporting people with Dementia – Section 8-10
- Supporting carers – Section 11
- Legislative change – Section 12
- Promoting research –Section 13

4.8 The Action Plan, attached to this document, links to one or more of the values and principles identified in this Section.

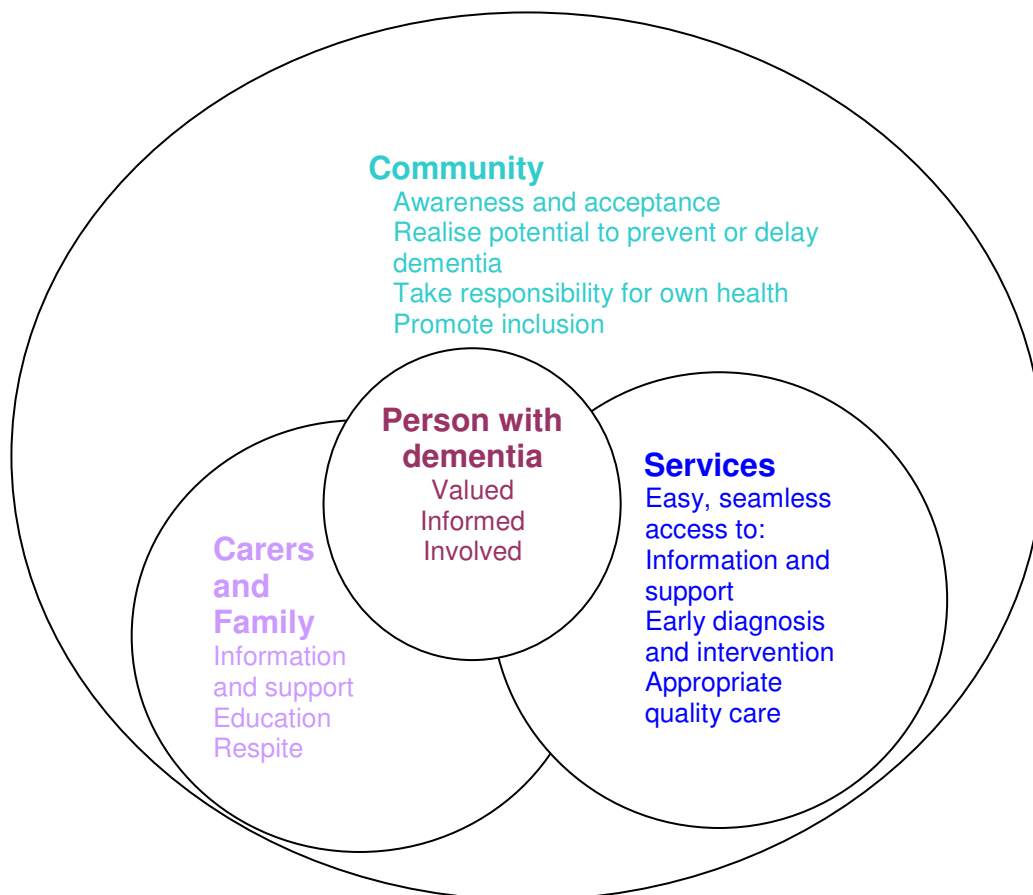
Section 5: A Model for Supporting People with Dementia and their Families

A Holistic Model for Supporting People with Dementia

5.1. In this model the individual with dementia is a valued member of society. Community, family, carers and services, including health and social care services, are developed around the person, so that support and care is “person centred”. For this to be successful requires:-

- Community - awareness and acceptance of dementia;
- Family and Carers - to be well informed and supported; and
- Services - to be seamless, accessible and proactive.

Chart 4: DEMENTIA CARE FOR THE WHOLE PERSON



5.2 Seeking and obtaining a diagnosis is the crucial starting point in the process towards effective and holistic care and support and the importance of early diagnosis is dealt with in detail in Section 7. After diagnosis, health and social care services must aim to provide care and support that promotes and preserves independence and maintains the usual patterns of daily living and family and wider social links as far as possible.

Person Centred Care

5.3 In assessing need and in planning and delivering care, it is essential to view the individual as a whole person, not simply as a set of symptoms. This means, first and foremost, taking the time to listen to and understand the person and to communicate effectively with them and their carers. The person with dementia needs to feel respected and valued for who they were in the past and for who they are now and to be reassured that they will continue to be respected and valued, no matter what their prognosis. Respect for their background, habits and customs allows them to retain a feeling of self-worth. It is also important to respect the person's and family's right to privacy as far as is practicable and to treat them with dignity.

Advocacy

5.4 People, particularly in the early stages of dementia, are often able to articulate their choices. But for some this may not be possible and there is a requirement on a wide range of people, including carers, family and health and social care professionals, to act in an advocacy role and ensure that the individual's views are respected.

5.5 People with dementia are at risk of being excluded from decisions that are made about their care. For them independent advocacy is one means of securing their involvement. A trained advocate can work with people in all

stages of dementia and has no role other than to help them to make informed choices and to communicate those choices.

- 5.6 Independent advocacy is particularly useful when the wishes of the person with dementia are in danger of being overruled or ignored by family, or professionals, particularly at times of transition from independent living.
- 5.7 Advocacy not only supports individuals; it also supports, fosters and develops best practice in dementia care. Where appropriate, independent advocacy should be available to people with dementia in order to support them in decision making, their families and carers and health and social care professionals who work with them.
- 5.8 In June 2011, DHSSPS published *A Draft Policy for Developing Advocacy Services – A Guide for Commissioners* for consultation. This draft policy aims to clarify what advocacy is, address the issue of independence and set out principles and standards to underpin the future commissioning and delivery of advocacy services in Northern Ireland. It also recognises the need for further guidance for the purposes of the new statutory right to an independent advocate to be provided for in the proposed new mental capacity legislation (see Section 12 for further detail). It is intended that this right will arise where a serious medical or welfare intervention is required but the person lacking capacity or their nominated person objects to the intervention. A key function of the advocate will be to try to ascertain the views of the person affected and ensure decision makers are aware of those views.

Action

DHSSPS will finalise the draft Policy for Developing Advocacy Services – A Guide for Commissioners and monitor its implementation.

Safeguarding for People with Dementia

5.9 People with dementia have the right to live their lives free from violence or abuse. Safeguarding people with dementia encompasses all the areas of work which enable a person with dementia to retain their independence, health and well being, and to live a life free from harm or fear of abuse, neglect or exploitation. Safeguarding is about ensuring environments and systems that prevent harm from occurring as well as promoting good practice across all agencies and providers in responding to concerns when they are raised.

5.10 Ongoing work to ensure that people with dementia receive all the assistance they need to keep them safe from harm and to be protected if harm occurs includes:

- Implementation of the Safeguarding Vulnerable Groups (Northern Ireland) Order 2007. This introduced new safeguarding arrangements by introducing a pre-employment vetting scheme and arrangements to bar unsuitable people from working with vulnerable adults and children;
- Implementation of Adult Safeguarding In Northern Ireland: Regional and Local Partnership Arrangements (2010). This established new structures to safeguard and protect vulnerable adults, including people with dementia;
- The development of separate Safeguarding Standards for inclusion in the Older Person's Health and Wellbeing Service Framework; and
- The development of a new regional policy on safeguarding adults at risk of harm or abuse, including people with dementia.

Service Planning

5.11 Involvement of individuals, families and communities is an important element of service planning. In their role as service commissioners, the Health and Social Care Board, the Public Health Agency and the Local Commissioning

Groups must involve people with dementia and their families and carers in decision making and in monitoring and evaluating the services provided.

- 5.12 For services to be person centred, people with dementia and their families and carers should be given the opportunity to design and receive services to suit their own needs through, for example, self-directed support. Direct Payments are cash payments given to a person in lieu of services that would otherwise have been arranged for them by a Trust, so that they may arrange the provision of their own services. Direct Payments allow greater flexibility for service users, allowing them to make arrangements with providers of their choice and at times convenient to them.
- 5.13 By giving people money in lieu of social care services, they have greater choice and control over their lives and are able to make their own decisions about how their care is delivered. Users are free to decide when, and in what form, services will be provided. They decide who comes into their home and becomes involved in very personal aspects of their lives. They are able to make their own decisions about how their care is delivered and how this support is shaped.
- 5.14 A Trust can offer a Direct Payment if it is satisfied that the recipient is able and willing to manage the payment, with help if needed. Direct Payments have been available to service users since 1996 and in 2004 were extended to a wider range of service users, including carers, under the Carers and Direct Payments Act (Northern Ireland) 2002.
- 5.15 Over the last few years the Department has been setting Direct Payment targets within its Priorities for Action to ensure that Trusts continue to promote the use of Direct Payments as an alternative to traditional social care provision.

Commissioning dementia services

- 5.16 New commissioning arrangements that have come into place through the reform of the health and social care structures will improve planning and commissioning of services, including dementia services, across the region. The Health and Social Care (Reform) Act (NI) 2009 introduced a requirement on the HSC Board and PHA to develop a joint commissioning plan describing how the allocated health and social care budget will be invested to meet Ministerial priorities and improve health and social wellbeing and outcomes.
- 5.17 In order to ensure that services are commissioned as locally as possible, the HSC Board will, where appropriate, devolve commissioning to Local Commissioning Groups (LCGs), who will commission services for the population in the geographical area they cover.
- 5.18 The HSC Board and PHA will draw up a service specification to inform regional and LCGs' commissioning for dementia care with a focus on service re-design. The specification will focus on:
- assessment of need, including carers' needs, and re-design of services and targeting of resources according to need; involving people with dementia and their families and carers, including promotion of advocacy and self directed support;
 - ensuring access to timely assessment and diagnosis with appropriate information and support;
 - promoting social inclusion of people with dementia through community based approaches;
 - adopting a care management approach with an emphasis on maximising the person's ability to live a purposeful life;
 - recognising the important contribution made by the independent sector and securing cost-effective use of the sector;
 - developing appropriate linkages across the HSC and with appropriate agencies outside the HSC to provide a seamless service from the user's point of view;

- developing standards for knowledge and skills of staff from basic awareness through to higher levels of qualification; and
- ensuring safety and quality of services

Service Delivery - A Staged Approach

5.19 The service specification will inform the quality of service delivery for dementia care. Dementia is a progressive condition, which calls for a staged approach to service delivery including prevention, early recognition, access to interventions, care and support, appropriate to the needs of the individual and their family, as illustrated in Table 3 below.

5.20 These stages form the basis for the analysis and proposed actions which follow in subsequent stages of this document. At all stages, care and support for dementia must be part of an integrated care management approach which encompasses all the needs of the individual, including physical, environmental, social and emotional needs, preserves people's functioning and prevents decline and takes into account the personal preferences and wishes of the person and family.

Table 3: DEMENTIA - A STAGED RESPONSE

**Stage
Prevention**

Awareness of avoidable factors

Supporting Processes

Health promotion messages at population level
Primary care health screening and preventative interventions at individual level

Early Recognition

Awareness of symptoms, knowledge of where to access help

Awareness raising at population level and addressing stigma
Advice and information services, particularly in voluntary and community sector

Initial assessment and diagnosis

GP and primary care team recognise possibility of dementia
Locally agreed pathways & protocols for referral to specialist services for diagnosis

Initial Management

Care & support with regular review

Advice and information services, particularly in voluntary and community sector, at initial stages and as required throughout all further stages
Support for individual and family to plan for the future
Multi-disciplinary support within primary care
Access to appropriate interventions, care and support
Carers needs assessed and met
In-reach from specialist services as appropriate

Referral to other agencies where appropriate

More significant needs develop

Early access to Specialist Team

Person Centred Care Plan, with care, as far as possible in own home, and with regular review

Locally agreed pathways & protocols for referral from primary care

Comprehensive, multi-disciplinary assessment, at home if possible, taking account of other health and social care needs (eg co-morbidities)

Access to appropriate interventions, care and support

Where admitted to hospital for assessment, focus on timely discharge to appropriate community setting, with appropriate communication and care plan to support the needs of the individual and their family.

Flexible supports developed within policy context of direct payments and personalised care budgets

Key worker identified to lead on co-ordination of multi-disciplinary care

Referral to and collaboration with other relevant agencies (eg, housing)

Arrangements for review of care plan

Carers needs assessment, where appropriate

Support in Times of Crisis
(eg, deterioration in condition, carer unable to provide care)

Short-term intensive support, as far as possible in own home

Intermediate care as “step up” where necessary

Where admission to hospital necessary for assessment and treatment, focus is on timely discharge to appropriate community setting, with appropriate communication and care plan to support the needs of the individual and their family.

Where admission to general hospital necessary, liaison services provided, including staff education and support

Multi-disciplinary review of Care Plan

End of Life Care

Palliative and end-of-life care and support to person with dementia and family

Summary

- 5.21 This section highlights a holistic model for individuals living with dementia into our society. A fundamental part of this is the promotion of awareness of dementia, risk reduction, early recognition, assessment, intervention, care and support. People with dementia, their families and carers should be involved in decision making, and advocacy should be available for those who need it.
- 5.22 The quality of dementia care is important. Therefore, there should be a regional approach to the development of a service specification to improve the commissioning and delivery of person-centred health and social care dementia services that will aim to maximise the person's ability to live a meaningful life. Given the progressive nature of dementia, service delivery needs to adopt a staged approach. The next section looks at the first key stage in this progression – making people aware of dementia and its impact on people's lives.
- 5.23 The main actions arising from this section are that:-

Action

HSC Board and Public Health Agency will draw up a service specification to inform regional and LCG commissioning for dementia care as outlined above.

DHSSPS, HSC Board and Public Health Agency will work with LCGs on a programme to improve understanding of the issues involved in commissioning dementia services.

Section 6: Raising Awareness of Dementia

Targeting Different Audiences

6.1 If we are to support people with dementia and their families as part of an inclusive society, there is a need to increase awareness of the condition. Three groups have been identified as targets:

- the general public on how to look after their own health, informing them on possible signs and symptoms of dementia and encouraging them to seek help early if they suspect they have memory problems;
- those working in services which interact with the public, so that staff know how best to respond to and support people with dementia; and
- those working in health and social care in the statutory and non-statutory sectors, both in dementia services and in the wider service, as many people with dementia have other health and social care needs too.

The General Public

6.2 Health promotion and disease prevention strategies have vital roles in meeting the challenges posed by dementia. Individuals, families and communities can take action on some of the established risk factors, as outlined in Section 4.

6.3 Members of the public also need to know about the signs and symptoms of dementia and be encouraged to seek help early. Reasons for not seeking help include stigma, views that nothing can be done about it and fears that having a diagnosis of dementia may lead to restrictions, such as not being able to drive.

- 6.4 Dementia strategies in neighbouring countries have also identified public awareness and social stigma as issues to be addressed. There is, therefore, scope for joint working, not just between government departments, agencies and the voluntary and community sectors, but also with other countries.

Action

Public Health Agency will draw up and lead on a plan to:

- address stigma;
- raise public awareness about what can be done to reduce the risk of or delay dementia; and
- raise public awareness of the signs and symptoms of dementia and about the benefits of seeking help early.

Public Services and Partnership Working

- 6.5 Any public information campaign that addresses stigma would also have an impact on people who deliver services to people with dementia. At a more strategic level, the HSC sector needs to work in partnership with other public bodies and with local community and voluntary sector bodies to challenge stigma relating to dementia and to encourage better understanding of the condition and its signs and symptoms among those providing services to the public.
- 6.6 A recent example of good practice in encouraging better understanding is the work carried out by Alzheimer's Society Foyle Branch with PSNI G District to train police officers in dementia awareness. The success of this pilot has led to plans to roll out the training across the PSNI.

Action

DHSSPS, HSC Board, Public Health Agency and HSC Trusts will work in partnership with other public bodies and with local community and voluntary sector bodies to challenge stigma relating to dementia and to encourage better understanding among those providing services to the public.

Health and Social Care Staff

- 6.7 People with dementia come into contact with a wide range of health and social care staff, many of whom do not work in services primarily aimed at people with dementia. There is clearly a training need within the health and social care sector, statutory and independent, across a broad spectrum of roles, both at pre qualification level and as part of continuous development. Some of this work, for example, changing undergraduate curricula, will take some time, but there are other elements which could be implemented more readily.
- 6.8 GPs and staff in primary care need to be able to identify the early symptoms of dementia and provide appropriate information, advice and referral. Staff providing services on a regular basis to people with dementia need an appropriate range of more specialised skills and knowledge in order to deliver high quality care. Later sections of this document also recognise the likelihood that people with dementia also have other health and social care needs but face particular difficulties in accessing and benefitting from the necessary services, acute hospital care being a prime example which is dealt with later in Section 9. Staff throughout the HSC who provide services frequently used by older people need to have an understanding of dementia and its impact so that they can respond to the person's needs. All of the above applies to staff in both statutory and non-statutory sectors.

- 6.9 Section 11 considers the needs of informal carers and recognises that they too need training in some aspects of their role, for example, in the use of assistive technologies.

Action

DHSSPS HR Directorate, HSC Board, Public Health Agency and HSC Trusts will co-ordinate a training and development plan across primary, community and secondary care, in statutory and non-statutory sectors, to improve knowledge and skills in providing care to people with dementia. This plan will include the needs of those providing informal care to people with dementia.

Summary

- 6.10 This section has looked at the need to make people more aware of dementia. Public awareness will reduce the stigma of dementia and will promote social inclusion for those who are living with dementia. It will also encourage those who suspect that they may be developing dementia to seek help as early as possible. Partnership working across all organisations in the public and independent sectors is important if service provision is to be integrated. Training of staff is essential to improve the skills and knowledge of staff. The next section looks at the arrangements that need to be in place to offer assessment and diagnosis to people who may have dementia.

Section 7: Initial Assessment and Diagnosis

The Importance of Early Diagnosis

7.1 Early diagnosis is important as it allows the person with dementia to:

- receive interventions which may slow the progression of the disease;
- receive care and support which may improve their quality of life; and
- make choices and plans for the future, with their family, while the condition still permits this.

The Listening Well exercise described in Section 2 identified this as a key issue.

Give me a final diagnosis, something that I can latch on to because I just feel lost.

Comment from Listening Well report

7.2 GPs are generally the first port of call for people worried about their health. GPs need to have a good knowledge of dementia and be aware of the importance of early diagnosis. In survey work carried out in Northern Ireland in support of a study of mental health services for older people¹⁹, less than half of all GPs in that survey thought they had enough training to diagnose and manage dementia. Only a very small number of GPs, however, have identified dementia as a learning need in their appraisal and review of training needs. Action is therefore required to improve GPs' knowledge and provide accessible information to them. At least some of this information needs to be local, for example, what services are available in their area.

7.3 The Dementia Services Development Centre's Northern Ireland Office has developed and distributed an information pack for GPs in Northern

¹⁹ Mental Health Services for Older People; Performance Review Unit, DHSSPS 2005

Ireland and this should be augmented with local information. GPs are identified in section 6 as one of the groups within health and social care services who need to improve their knowledge and skills in relation to dementia.

Who Should Provide The Initial Diagnosis?

7.4 Evidence suggests that GPs in Northern Ireland are still making a diagnosis of dementia for some people, despite the recommendation from the 1995 policy review which stated that those suspected of having dementia should be referred for specialist assessment.

Possible reasons for this are:

- lack of knowledge of the specialist service available;
- lack of appreciation of the benefits of a specialist diagnostic service and, in some cases, specialist care and support services beyond diagnosis;
- lack of capacity of the specialist service to deal with all referrals; and
- uncertainty about when a referral to the specialist service is appropriate.

7.5 To provide guidance to GPs, the HSC Board in collaboration with the Public Health Agency and HSC Trusts will draw up criteria for referral to the memory service, taking into account:

- the potential benefits of specialist care, support and advice to the person and their carers; and
- the capacity of specialist services to deal with the anticipated increase in referrals as the ageing population grows.

Actions

Trusts will supplement the GP information pack produced by the Dementia Services Development Centre – Northern Ireland with information on the local services available.

HSC Board in collaboration with the Public Health Agency and HSC Trusts will draw up criteria and clear protocols for referral from GPs to the memory service.

Access to Special Services for Assessment and Diagnosis

- 7.6 The English Department of Health's National Dementia Strategy²⁰ also advocates that the role of primary care should be to identify those people who are presenting with possible dementia and, having eliminated other possible conditions, refer them to a specialist dementia diagnostic service with a single focus. This is in line with the 1995 Northern Ireland Dementia Policy Review recommendation.
- 7.7 Information provided by the Trusts indicates that services dealing with assessment and diagnosis of memory problems are available in each Trust. These services are provided through sessional clinics held at a variety of locations - mostly hospitals and health centres - across each Trust and are led by a variety of professionals; some by consultant psychiatrists, some by consultant geriatricians and some nurse-led. Most services are accessed via GP referral, but at least one service reported accepting open referrals. Although a large proportion of people being seen at these memory services present with dementia, the services deal with other memory problems too.
- 7.8 Currently some memory services provide assessment and diagnostic services only. The preferred model is one which provides access to a range of care, support and advice before and after diagnosis. A minimum range of care, support and advice services to be provided by a memory service should be agreed regionally. Memory services should be developed to meet local needs, based on this agreed

²⁰ Living Well with Dementia: A National Dementia Strategy; Department of Health 2009

minimum range of services and in line with the principles outlined in the Table below.

Table 4: Principles of a Memory Service

Principles of a Memory Service

The memory service is accessible to people with memory problems and their carers.

The memory service is designed and managed so that the respect and dignity of people with memory problems/dementia and their carers is preserved.

Memory service staff work effectively as a multidisciplinary team.

There are sufficient numbers of appropriately skilled and qualified for their jobs, and their continuing professional development is facilitated.

The memory service works closely with other professionals, agencies and providers to support the processes of assessment and diagnosis.

The memory service offers a range of supports to promote early identification and referral into the service.

Any clinic run by the memory service is accommodated in an environment that is appropriate to the needs of people with memory problems/dementia.

Any clinic run by the memory service provides the necessary facilities and resources for staff to effectively carry out their duties.

The memory service provides timely access to assessment and diagnosis.

Staff follow clear procedures for gaining consent and ensure that people with memory problems/dementia are well-informed of their rights regarding consent.

Personal information is kept confidential unless this is detrimental to the person's care.

The outcome of the assessment is communicated to all relevant parties in a timely manner.

The memory service is able to offer appropriate advice, information and support, including counselling, to people with memory problems/dementia and their carers at the time of assessment and diagnosis.

Professionals working within the memory service ensure that the person (and their carer, where appropriate) is able to access a range of post-diagnostic

supports and interventions, including counselling.

The memory service ensures that each person with memory problems/dementia is followed up.

Source: Royal College of Psychiatrists

- 7.9 Recognising that there will be a small number of cases where diagnosis is complex, for example, with atypical forms of dementia or in younger people, memory services should have access to a regional memory service providing specialist expertise and further investigations for such cases. This tertiary service should be led by one Trust with an agreed referral mechanism from local memory services.

Actions

HSC Board in collaboration with LCGs, Public Health Agency and Trusts will agree on a minimum range of services that a Memory Service should provide, regardless of whether the service is community- or hospital-based.

Trusts will ensure that memory services meet the principles outlined in Table 4 above and ensure that the agreed minimum services are available for people in their area.

For complex cases, including atypical forms of presentation of dementia, a regional tertiary service should be available; this should be led by one Trust with agreed referral criteria from local memory services.

After allowing time for development of the services as outlined in actions above, the Regulation and Quality Improvement Authority (RQIA) will conduct a review of the effectiveness of memory services available in each Trust.

Summary

- 7.10 Each Trust currently has a memory service available. This section highlights the importance of appropriate referral from general practice for specialist assessment and diagnosis. All memory services should comply with the principles outlined in this section. For those individuals who require further specialist investigation, a regional tertiary service, led by one Trust should be available with referral from a local memory service.
- 7.11 Once a person has been diagnosed with dementia, they need information and support and access to care services. The provision of these services is considered in the next section.

Section 8: Supporting People with Dementia

- 8.1 As already outlined, the care and support offered to people with dementia and their families and carers needs to be person centred, respecting the person's individual circumstances, needs and wishes and promoting and preserving their rights.

Information and Support at Time of Diagnosis

- 8.2 Getting a diagnosis of dementia is often distressing and the way in which information, advice and support are offered can make a big difference in helping people cope with the diagnosis.

'You have dementia and sorry about that.' That was really it... no more information at all about it.

Comment from Listening Well report

- 8.3 Information provided by Trusts during the development of this strategy suggests that advice and support at the time of diagnosis is a role which may fall to the memory service team, other community teams that provide care for people with dementia or to services provided by the voluntary sector. Staff need the knowledge, skills and competency to carry out their role sensitively²¹.
- 8.4 One of the principles of a memory service shown in Table 4 above relates to the service's ability to provide appropriate support, advice and information that is timely and tailored to the needs of the person with dementia and their carers. This should, therefore, feature in the minimum range of services referred to in the preceding Section.

²¹ Breaking Bad News Guidelines; DHSSPS 2003

Action

Trusts will ensure that memory services provide advice and information services and are able to signpost to other relevant advice and information services.

Initial Care and Support

- 8.5 The immediate needs of someone who has recently received a diagnosis will vary considerably, depending on the stage of their dementia and other individual needs. For those in the early stages, initial requirements may be solely for information and advice, with a contact point should they wish to ask further questions later or to seek help as their condition deteriorates. Consistent advice is important.
- 8.6 Under the Quality and Outcomes Framework (QOF), GPs are incentivised to maintain a register of people in their practice who are diagnosed as having dementia. In 2010/11 over 11,000 people were on dementia registers held by GPs in Northern Ireland – just over half of the estimated number of people here who have dementia. This is a higher proportion than in England, where an estimated 40% of people with dementia are on GP registers. It is lower than Scotland which was met a target of increasing the numbers of people with dementia on the register by 30% over the last three years. There is, however, no indication of the stage at which people are receiving a diagnosis and being placed on the registers.
- 8.7 The Quality and Outcomes Framework also provides for 15 monthly reviews of people on the dementia registers. The reviews are designed to address four key issues:
- an appropriate physical and mental health review for the patient;

- if applicable, the carer's needs for information commensurate with the stage of the condition and their and the patient's health and social care needs;
- if applicable, the impact of caring on the care-giver; and
- communication and co-ordination arrangements with secondary care, if applicable.

At March 2010 almost 80% of eligible patients in Northern Ireland practices had been reviewed in the previous 15 months.

- 8.8 In order to maximise the benefit of the 15 month review, the HSC Board, in collaboration with the Public Health Agency, will consider how to further develop secondary prevention in the context of the dementia indicator in QOF (Section 3).

Multi-disciplinary Approach to Meeting Need

- 8.9 A key objective of this strategy is to enable the person with dementia and their carers to promote independence and maintain the person's optimum level of functioning in terms of physical skills, cognitive skills, emotional and psychological well being. To achieve this, people may require care and support from a wide range of health and social care services to promote independent living. Their carers may also require support.

With the diagnosis should come a package or something that says, you know, this is what you have got and this is what is available, this is what you'll need. Everything like from medical through to personal care, through to money, through to financial.

Comment from Listening Well report

- 8.10 A multi-disciplinary approach is therefore required in assessing need (including carer's needs), drawing up and reviewing a care plan and appointing a key worker. Trusts need to ensure that there are clear local referral pathways from GPs and, where necessary, from memory

services to the multi-disciplinary teams responsible for assessment and from these teams to other appropriate care and support services.

- 8.11 The introduction of the Northern Ireland Single Assessment Tool (NISAT) for assessing the health and social care needs of older people will promote a more uniform and structured approach to needs assessment. The implementation of NISAT is ongoing across all Trusts in Northern Ireland with full implementation for use in the care of older people, including those with dementia, expected towards the end of 2011. (NISAT also includes a component for assessing the needs of carers – see paragraph 11.3.)

Action

Trusts will ensure that all people with a diagnosis of dementia who seek services have a care plan drawn up and reviewed in line with the Northern Ireland Single Assessment Tool (NISAT).

Preserving Skills and Functioning

- 8.12 Dementia is characterised by a gradual impairment of skills and an increasing inability to engage in purposeful behaviour. It is vital that those providing care and support use a range of interventions to enable the person with dementia to continue to engage in meaningful and purposeful activity and live as independently as possible. As the condition progresses, the person will require ongoing support to adjust and adapt activities to help them continue to achieve.
- 8.13 Emerging research shows that engagement of people with dementia in activities suited to their capabilities improves quality of life for both them and their caregivers. Attention must be focused on the whole person and may include modifying environments, simplifying tasks, establishing structure and routine, practicing tasks through repetition,

using effective cueing and communication strategies, assistive technology, skills training and education of family and caregivers.

Action

The HSC Board and PHA will ensure that a range of provision is developed to help people preserve their functioning and prevent decline.

Medication and Other Interventions

When she went on [named drug] the quality of life was definitely in her case increased by the use of this drug.

Comment from Listening Well report

- 8.14 NICE guidance²² currently recommends the use of the drugs donepezil, galantamine and rivastigmine as options in the care of people who have mild to moderate stage Alzheimer’s disease. Memantine is recommended as an option for people with severe Alzheimer’s disease and those with moderate Alzheimer’s disease who cannot take donepezil, galantamine or rivastigmine. The guidance specifies that only specialists in the care of people with dementia should initiate drug treatment and that patients should only continue to take these drugs while they, their doctors and their family or carers agree they are having a worthwhile effect on the symptoms. Patients should be reviewed regularly using cognitive, global, functional and behavioural assessment. This guidance has recently been endorsed as applicable in NI.

²² Technology appraisal guidance 217 - “Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer’s disease” NICE 2011

- 8.15 In 2010 over 84,000 prescriptions were issued in Northern Ireland for these drugs with an ingredient cost of £7m, the most common being donepezil, accounting for about 40% of the number of prescriptions and 45% of the total cost. Alzheimer's drugs account for over 1% of the total drugs bill.
- 8.16 There are concerns about the use of antipsychotic drugs among people with dementia for the management of behavioural and psychological symptoms, such as hallucinations, delusions, anxiety, agitation and associated aggressive behaviour. NICE guidance recommends the use of medication for such symptoms only if there is severe distress or an immediate risk of harm to the person or to others. It is estimated that only 20% of people with dementia being treated with antipsychotic medication in England will derive some benefit from the treatment²³. Set against this are the negative effects directly attributable to the use of antipsychotic medication, including additional strokes and additional deaths.
- 8.17 Work has been carried out as part of the Pharmaceutical Clinical Effectiveness Programme in NI by the Regional Psychiatry Expert Group to:
- develop guidance on the physical health monitoring required for patients prescribed antipsychotic drugs to ensure a standard approach across primary and secondary care; and
 - develop guidance on the wider prescribing issues associated with antipsychotic medicines.
- The guidelines are awaiting approval by the newly convened Medicines Management Forum established by the HSC Board.
- 8.18 NICE guidance identifies a range of therapeutic interventions other than antipsychotic medication that should be available to people with

²³The use of antipsychotic medication for people with dementia: Time for Action; Banerjee S.; Department of Health (2009)

dementia to treat their distress and agitation. In order to inform decisions on appropriate intervention the guidance also identifies factors that may affect their behaviour. The range of therapeutic interventions, including psychological therapies, available in Trusts is varied. The potential of psychological therapies to improve outcomes for individuals, families and carers is recognised in the DHSSPS strategy for improving access to psychological therapies in 2010²⁴, implementation of which will benefit people with dementia and their carers, among others.

Action

The HSC Board and PHA will ensure that medication for the management of dementia is prescribed appropriately, that medication review is an integral part of the care management process and that a range of therapeutic interventions are available to people with dementia and their carers appropriate to their assessed needs.

The HSC Board and PHA will conduct a subsequent audit of the interventions available for dementia care across all settings, including nursing and residential care.

Short Break Care for Respite

8.19 Trusts provide a range of short break care including services in the person's own home, day activities outside the person's own home and in residential and nursing homes. The provision of regular, planned respite is a valuable support to both the person with dementia and carers, as is the "safety net" of short break care to help cope with emergency situations, should they arise.

²⁴ A Strategy for the Development of Psychological Therapies in Northern Ireland; DHSSPS, 2010

- 8.20 The Bamford review²⁵ highlighted gaps in domiciliary based respite care in particular and called for a broad range of respite services to be established. Additional funding has been allocated over the period 2008/09 – 2010/11 to provide, by March 2011, an additional 1200 weeks of dementia respite care.
- 8.21 In developing additional short break provision it is important that innovative services are encouraged, maximising the potential of community-based options and the use of direct payments.

Action

The HSC Board and PHA will ensure that a range of both traditional and innovative short break provision is developed to meet the needs of people with dementia and their carers.

Environmental Design

- 8.22 NICE – SCIE guidance²⁶ recognises the importance of design of living and care environments to people with dementia. Good practice in environmental design involves using an audit tool at the design or refurbishment phase to make sure that architecture and design choices are informed by research and internationally recognised best practice in dementia design.

²⁵ Living Fuller Lives; Bamford Review of Mental Health and Learning Disability (Northern Ireland) 2007

²⁶ Dementia: supporting people with dementia and their carers in health and social care; Clinical Guideline 42, NICE 2006 (Amended March 2011)

Action

The HSC Board, in conjunction with the Public Health Agency, DHSSPS Health Estates Group and the Dementia Services Development Centre – NI, will develop environmental standards for all new facilities providing care solely or mainly for people with dementia.

The HSC Board will lead on a programme of environmental assessment of existing facilities used by people with dementia and draw up a prioritised improvement plan for action as resources permit.

Housing Adaptations

8.23 Adaptations to the home can make it easier for the person with dementia to remain there. This might include making it easier for the person to move around the house, easier access to a shower and toilet, communication and security equipment. Such adaptations and technologies can be made available following an assessment of the person's need by the relevant HSC Trust.

Assistive Technologies

8.24 Trusts report access to a wide range of assistive technologies, including some access to telecare and telemonitoring for other health problems. Some of this is accessed through supported housing schemes. Further information about assistive technologies can be found at Appendix 3.

8.25 Use of these technologies must be informed by evidence of their effectiveness, particularly as new technologies develop. Careful assessment of their applicability is needed, balancing the rights of the person with dementia with the intrusive nature of some technologies.

People who are being asked to use assistive technologies need to be trained and supported in using them to best effect.

- 8.26 A number of suppliers of these technologies are being used by Trusts and housing providers and there is the potential for economies of scale through regional procurement. Work to establish an evidence base for their effectiveness in dementia care will be undertaken to inform procurement.

Actions

The Public Health Agency will commission a literature review on the cost effectiveness of assistive technologies in supporting people with dementia.

This review will inform a regional procurement approach by Trusts, in collaboration with housing providers.

Supported Housing

- 8.27 For people with dementia who are no longer able to live independently within their own home, supported housing offers a viable alternative to residential care. A key benefit for the person is that they continue to live independently within a safe and secure environment, with care and support available from a dedicated staff over a 24 hour period. The social and built environment is designed to compensate for the person's disability, to promote orientation and enhance the person's feelings of well-being.
- 8.28 For many people a diagnosis of dementia can mean social exclusion. Supported housing schemes aim to reduce the stigma attached to a diagnosis of dementia through a community based model which offers the person their own tenancy with a housing association and promotes

the person's experience through involvement in routine daily living activities. Emphasis is placed on working in partnership with families and on building and maintaining links with the local community, fostering a more positive public perception of dementia.

- 8.29 There are currently 5 supported housing schemes for people with dementia in Northern Ireland. Four of these have been developed in a partnership between a Health and Social Care Trust and a Housing Association. These schemes are part funded through the NI Housing Executive by the Department for Social Development's Supporting People Fund.
- 8.30 There is potential to promote further the benefits of supported housing, particularly exploiting the use of telecare, to support more people with dementia in living as independently as possible.
- 8.31 An Inter-Departmental Group with membership from the Department for Social Development, Northern Ireland Housing Executive, DHSSPS and the HSC Board currently meets to discuss and take forward a range of issues on supported housing matters. Comprehensive needs assessment for supported housing provision across all Trusts is being undertaken to identify strategic priorities and assess the capital and revenue costs, both Supporting People and health and social care costs. Future need for supported housing for people with dementia is being taken in to account in this work and will also be taken into account in the proposed service specification to inform commissioning for dementia care referred to earlier in Section 5.

Actions

DHSSPS and the HSC Board to continue to work with DSD and the NI Housing Executive on supported housing matters and to agree on priorities in line with available capital and revenue resources.

HSC Board and the PHA to collaborate with DSD and the NI Housing Executive on how supported housing can be included in their work on the service specification.

Crisis Support and Intermediate Care

8.32 For people with dementia, a time of crisis may occur because of a rapid deterioration of the symptoms associated with their dementia or a co-existing physical health problem. The aim is to support the person and their carers so that, as far as possible, the person can remain in their own home environment. Dementia must not be seen as a reason for excluding people from intensive home care and support in times of a crisis.

The further development of intermediate care will promote rehabilitation and independent living in a way that will see a shift away from traditional residential and nursing home care towards flexible and responsive domiciliary care services wherever possible.

DHSSPS Priorities for Action 2009-10

8.33 Intermediate care is designed to prevent unnecessary hospital admission, support timely discharge and maximise independent living. It is targeted care for people who would otherwise face inappropriate admission to acute in-patient care, unnecessarily prolonged hospital stays or long-term residential/nursing home care. Intermediate care must be provided on the basis of a comprehensive person-centred assessment of need, with a planned outcome of maximising independence and typically enabling service users to remain or resume

living at home. The care is time-limited, usually no longer than six weeks and frequently as little as 1-2 weeks or less.

- 8.34 Intermediate care can provide an alternative to inappropriate admissions and a bridge to effective acute intervention. It can serve to improve the quality of decision making about long term health and social care needs because it provides an opportunity for rehabilitation. Intermediate care also has the potential to provide the right environment for fully integrated multi-disciplinary working and delivering flexible and responsive services.
- 8.35 In view of the high levels of demand on acute hospital services by people with dementia and their poor experiences in these settings at present (see Section 9), people with dementia are likely to benefit significantly from increased access to intermediate care provided by suitably skilled staff.
- 8.36 Trusts report little or no current access to intermediate care provision for people with dementia, although several indicated ongoing work within their Trust to develop intermediate care provision, within which dementia services would feature.

Actions

Trusts will ensure that appropriate care pathways are developed to ensure that people with dementia have access to services equipped to respond to crisis, including intermediate care.

Inpatient Care

- 8.37 Some people will require admission to a mental health or geriatric unit for assessment, which will often include addressing medication and behavioural issues. The focus of such admissions must be on assessing the person's needs and putting in place any necessary

interventions. Any hospital stay must be short-term with a view to timely discharge, through returning to the person's former home or securing a more suitable placement to meet their continuing needs.

- 8.38 There are currently over 200 beds in mental health facilities designated for dementia assessment, although there are plans in at least some Trusts to reduce these. An analysis of the length of stay of current inpatients shows that almost half of these patients had been in hospital for more than 3 months, with some having been there for considerably longer. The requirement for dementia assessment beds across Northern Ireland will be considered in the work to inform commissioning for dementia care referred to in Section 5, recognising the potential to redirect resources away from inpatient to community based dementia care.

Actions

Trusts will review current hospital bed provision for dementia assessment and harmonise provision across Trusts with an emphasis on developing assessment services in the community.

Palliative and End of Life Care

- 8.39 Research shows that approximately two-thirds of people in the UK would, if they had a terminal illness, prefer to die at home, yet for many this is not possible currently. Services for patients with palliative and end of life care needs have developed considerably over the past decade. Management of pain and other physical symptoms and provision of psychological, social and spiritual support for both the person and their family and carers are key elements of such care.

8.40 The DHSSPS 5 year strategy for Palliative and End of Life Care²⁷ sets out a vision for palliative and end of life care across all conditions and care settings based on what people value most and expect from such care. This vision emphasises the importance of:

- understanding palliative and end of life care;
- best and appropriate care supported by responsive and competent staff;
- recognising and talking about what matters;
- timely information and choice;
- co-ordinated care, support and continuity.

The strategy's recommendations have been built into an Action Plan to enable the planning and delivery of quality palliative and end of life care.

8.41 In support of the strategy Trusts have multi-disciplinary palliative and end of life care teams in place. It will be important to ensure that team members have awareness of the needs of people with dementia. There is evidence of team members in at least one Trust receiving dementia training, but this should be the case in all Trusts.

Action

Trusts to develop palliative and end of life services for people with dementia within the framework of the palliative and end of life care strategy.

People Under 65 with Dementia

8.42 Some people aged under 65 have dementia - often referred to as early onset dementia - many of whom have one of the rarer and more unusual types. Estimates of the numbers affected in Northern Ireland range from 400 to 1000.

²⁷ Living Matters, Dying Matters – A Palliative and End of Life Care Strategy for Adults in Northern Ireland, DHSSPS 2010

- 8.43 Diagnosis is essentially the same as for those over the age of 65 but may be complicated by elimination of other possible conditions and risks posed by work and dependant children. Dementia is a particularly difficult diagnosis for younger people to receive, as they will often be in employment, have a family to support and have financial commitments. Moreover, many of the services available for older people with dementia are inappropriate to people with early onset dementia.
- 8.44 A specific care pathway for younger people with dementia should, therefore, be developed on a regional basis, in view of their particular needs. Where appropriate to do so, this should link in to a regional tertiary service (see section 7), where referral for assessment of more complex conditions and second opinion can be obtained.

Action

Trusts will work together to develop a regional care pathway for younger people with dementia.

People with a Learning Disability and Dementia

- 8.45 The prevalence of dementia in people who have learning disabilities is estimated to be 4 times higher than the general population. People who have Down's Syndrome are particularly vulnerable to developing dementia and will develop the condition at a younger age (some in their thirties) and with a much higher and increasing prevalence as they age. Some Trusts have introduced screening programmes for dementia for people with Down's Syndrome.
- 8.46 Every single element of this strategy will also apply to people with a learning disability, in the context of awareness raising and training, identification and early intervention, the provision of information, the

availability of advocacy, a full range of medical and other interventions, and the importance of multi-disciplinary, multi-agency working. All mainstream diagnostic and support services will be expected to make the necessary reasonable adjustments to enable access by people with learning disabilities and, as part of this requirement, will need to review the skills and competencies of staff within these services.

- 8.47 However, recognising that people with learning disabilities will already have an established connection and a history of support from learning disability services, these services should continue to take a lead role in the planning and coordination of support.

Actions

Trusts will ensure that people with a learning disability and dementia are supported by learning disability services, with access to the full range of specialist dementia services to meet individual needs.

Specialist dementia diagnostic and support services will provide the necessary reasonable adjustments to enable full access by people with learning disabilities.

Rarer Causes of Dementia

- 8.48 There are a number of rarer diseases and conditions that can lead to dementia. These include Huntington's disease, multiple sclerosis, Parkinson's disease and Korsakoff's syndrome. Inherited disorders such as Niemann-Pick disease can also lead to dementia. The need for appropriate referral to genetic services for people likely to have a genetic basis to their dementia has already been referred to in Section 3.

Summary

- 8.49 This section concentrates on the needs of people living with dementia in their own homes. It highlights the importance of integrated working to support individuals, families and carers. This includes the provision of timely information, enhanced respite and intermediate care, and appropriate home environments which support individuals to live as independently as possible.
- 8.50 A significant number of people with dementia, however, are in acute hospitals at any one time and the next section highlights the need to improve their experience while in hospital.

Section 9: Supporting People with Dementia in Acute Hospitals

- 9.1 Admission to hospital is a stressful time for anyone and can be even more so for a person with dementia; the distress and confusion caused by admission to hospital added to the difficulties experienced in even the most basic areas of getting adequate food and drink often lead to a longer stay in hospital and to poorer outcomes.
- 9.2 In 2007/08 over half (56%) of acute hospital beds in Northern Ireland were occupied by people aged 65 and over. Based on research findings that up to 40% of these people have dementia²⁸, up to 25% of all inpatients in acute hospitals on any day may have dementia. In 2007/08 however less than 5% of inpatients on any day in Northern Ireland had a diagnosis of dementia recorded. This would suggest that the fact that a person has dementia is often not recognised or considered important in their care in an acute ward.
- 9.3 The Counting the Cost report²⁹ found an unacceptable variation in the quality of dementia care on general wards in England, Wales and Northern Ireland. The report found that people with dementia stay far longer in hospital than other people who go in for the same procedure and noted a correlation between the time people with dementia stay in the acute environment and the detrimental effect on the symptoms of dementia and on the individual's physical health. These factors combine to place additional pressures on the health service.
- 9.4 The report concluded that, with further support, people with dementia could leave hospital one week earlier resulting in large monetary savings and in considerable benefit to the patients' overall physical and

²⁸ Psychiatric illness predicts poor outcome after surgery for hip fracture: a prospective cohort study; Holmes J and House A (2000), *Psychological Medicine*, 30, 4, 921–929.

²⁹ Counting the Cost: Caring for people with dementia on hospital wards; Alzheimer's Society (2009)

mental health. The report recommended reinvestment of these resources in workforce capacity and skilling and in community services.

9.5 While improved crisis services and intermediate care should enable more people with dementia to remain in the community, there will be times when admission to hospital is the most appropriate option. Mechanisms to identify people with dementia at the point of admission to acute hospitals is essential so that a specific approach to their care while in hospital is provided. Hence, information sharing between primary and secondary care is vital. Appropriate care and support while in hospital is likely to involve a wide range of professionals and require co-ordination. A care plan should be drawn up for every person with dementia admitted to hospital, focusing on provision of the dementia-specific supports required to support timely treatment and discharge.

9.6 Many of the issues already identified on support for people with dementia apply to caring for people in acute hospitals as to people in their own homes – issues relating to:

- a person centred and multi-disciplinary approach;
- provision of information to the person and their family;
- staff knowledge and skills;
- preserving function and skills and preventing decline;
- appropriate use of medication and other interventions; and
- environmental design.

Actions in the action plan must therefore encompass, where appropriate, services provided in acute hospitals.

9.7 The Dementia Services Development Centre's Northern Ireland Office has developed an acute care pack for HSC Trusts to enhance knowledge on dementia and skills of staff working in the acute sector. It will raise awareness on the specific needs of individuals with dementia when they are admitted to an acute ward.

Action

The Dementia Services Development Centre (Northern Ireland) will work with HSC Trusts to enhance knowledge and skills on the care of individuals with dementia, when admitted to acute wards.

Trusts will ensure that an individual care plan is drawn up for each person with dementia admitted to an acute hospital setting, focusing on the dementia-specific supports necessary to ensure appropriate care in and timely discharge from hospital.

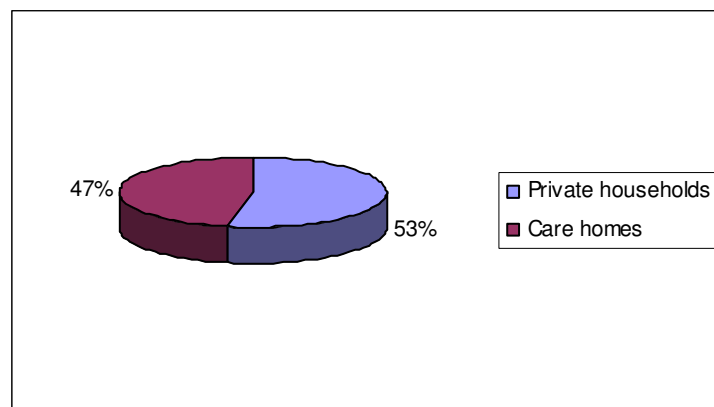
Summary

- 9.8 This section highlights the importance of understanding the care needs of individuals with dementia when they are admitted to an acute hospital ward. In order to enhance the quality of care and improve outcomes, all such individuals should have a specific care plan in place. An “acute care pack” will be produced to enhance care in these settings.
- 9.9 The next section looks at what needs to be done to improve care when people with dementia are admitted to care homes.

Section 10: Supporting People with Dementia in Residential and Nursing Homes

10.1 Reliance on care homes is much higher here than in the rest of the UK. Almost half of all people with dementia in Northern Ireland are in care homes³⁰, much of this provided by the independent sector. The proportion of those with dementia living in care homes rises steadily with age, from 39% of those aged 65-74 to 68% of those aged 90 and over.

Chart 5: Living arrangements of people in NI with dementia



Source: Dementia UK report

10.2 Care for people with dementia can be provided either in homes specifically designated for people with dementia or in homes designated as providing care for older people in general. The Regulation and Quality Improvement Authority (RQIA) is responsible for regulating this sector, thus promoting compliance with agreed regional standards of care.

10.3 Many of the issues already identified in Section 8 on support for people with dementia apply to caring for people in care homes as well as to people in their own homes – issues relating to:

³⁰ Dementia UK – Northern Ireland Supplement; LSE, King’s College London and Alzheimer’s Society 2007

- a person centred and multi-disciplinary approach;
- provision of information to the person and their family;
- preserving function and skills and preventing decline;
- appropriate use of medication and other interventions;
- environmental design and use of assistive technologies; and
- crisis support.

10.4 Staff competence in caring for people with dementia is a key factor in the quality of experience of those in care homes, as in other health and care settings. This includes the ability to care for the whole person, with awareness of the person's background, history and personal preferences, and appropriate responses to physical health needs, pain management, depression and other mental health conditions. The training and development needs of care home staff will be included in the action proposed in Section 6 on a training and development plan for staff in all sectors.

10.5 As in other settings, environmental design can have a significant impact on the quality of life for people in care homes. Prescribing a drug is the most common medical intervention experienced by elderly residents in nursing and residential care homes.

10.6 A Northern Ireland study³¹ has shown that almost 50% of residents were receiving 10 or more medications, 65% were receiving psychoactive medication and for over 70% of these residents no reason was documented for such medication. Further research is under way, including a study to examine the influence that organisational culture within homes may have on prescribing.

³¹ Patterson S M, Hughes C M, Crealey G, Caerdwell C, Lapane K. An evaluation of an adapted United States model of pharmaceutical care to improve psychoactive prescribing for nursing home residents in Northern Ireland (Fleetwood NI Study). *Journal of the American Geriatrics Society* 2010; **58**: 44-53

- 10.7 The work referred to in Section 8 on ensuring that medication for the management of dementia is prescribed appropriately, that medication review is an integral part of the care management process and that a range of therapeutic interventions are available to people with dementia appropriate to their needs will encompass care in care homes.
- 10.8 Standards for commissioning care in care homes should encompass:
- staff knowledge in relation to dementia, uptake of up to date training sessions and application of research findings to cover, for example, dementia care mapping, person centred care and general information on the range of dementias;
 - environmental audit of homes and plans to make homes more dementia friendly;
 - review of psychotropic and night medication use in homes;
 - life history work with each individual being cared for in the homes, in conjunction with their families and carers;
 - physical health needs assessment to include, for example, pain and depression, using recognised assessment tools;
 - dining experience, reviewing nutrition, mealtimes, hydration and dignity at and between mealtimes;
 - training for staff on dealing with distressed reactions and how to monitor and manage episodes in homes; and
 - building effective links between community based dementia services and care homes.

Action

The HSC Board, in collaboration with the PHA and Trusts, will develop standards, which include the areas outlined above, for commissioning dementia care in care homes. These will be incorporated into the service specification to inform commissioning for dementia services.

Summary

- 10.9 This section recognises that the quality of care provided in care home settings can be further enhanced through the training and commitment of staff and through an agreed approach to commissioning standards for the provision of care in this sector.
- 10.10 The sections to date have concentrated on the person with dementia. The next section considers the needs of those family and friends who provide informal care.

Section 11: Supporting Carers

I have such support from [partner] that I don't know how I would manage to live if she weren't around. I would be getting lost... repeating myself over and over... forgetting.

Comment from Listening Well report

- 11.1 For those who are living at home, a substantial amount of dementia care is provided by family and other carers. Caring for someone with dementia can be a difficult and demanding task. When the carers do not understand the diagnosis or the future implications of the condition, the caring burden is greater. Building up community capacity to maintain people with dementia in their homes safely for as long as possible requires effective and accessible awareness training, embracing all those affected by dementia and who are involved in care and support.

My problem now is that I am the resource and I ain't supported and I ain't gonna last.

Comment from Listening Well report

- 11.2 The Carers and Direct Payments Act (Northern Ireland) 2002 imposed a duty on HSC Trusts to inform carers of their right to an assessment of their own needs. Such assessments give carers the opportunity to discuss and to plan for what they need by way of emotional, practical and financial support to help them continue in their caring role. In 2006 the Department published a carers' strategy, Caring for Carers³², which is an inter-agency strategy, dealing with health and personal social services, employment, training, education, availability of information and support services for carers.

³² *Caring for Carers: Recognising, Valuing and Supporting the Carer's Role: DHSSPS 2006*

11.3 As part of the work to develop the Northern Ireland Single Assessment Tool (NISAT) for assessing the health and social care needs of older people, a separate tool has been developed for carer's assessment – the Carer's Support and Needs Assessment. This covers:

- the impact of the caring role on the carer;
- social security benefits received and the need for information about benefits or financial planning;
- the use of Direct Payments as a vehicle for personalised service delivery;
- contingency planning;
- issues for the future;
- unmet need; and
- consent to information sharing and any restrictions to this.

11.4 Since December 2009 all Trusts have been required to use this assessment tool to assess the needs of all carers of adults, including those with dementia. This will promote a common approach across Trusts to the assessment of carers' needs.

11.5 A joint DHSSPS/DSD review of the support provisions for carers was carried out and its findings published in November 2009³³.

Recommendations include:

- strengthening the Carers' Strategy Implementation Group;
- rolling out the Carer's Support and Needs Assessment component of the NI Single Assessment Tool (NISAT) with older people's services being targeted by 2010;
- promoting use of the Trust self audit tool to support implementation of Caring for Carers;
- commissioning from RQIA a thematic inspection of carers' issues;
- updating the A-Z for Carers;
- improving information collection on services for carers;

³³ Review of support services for carers; DHSSPS and DSD (2009)

- seeking ways to support carers through training in the more technical aspects of their role;
- seeking ways to improve provision of breaks for carers, including emergency situations;
- improving access to emergency respite cover;
- monitoring the DoH demonstrator sites in relation to carers support and;
- working more closely with DSD in providing information and signposting for carers.

11.6 Action to support those caring for people with dementia will be taken in the context of this wider review.

Actions

Trusts will continue to implement the NISAT carer's assessment tool in respect of those caring for people with dementia.

Trusts will develop support, including practical, educational and, where appropriate, psychological support to those caring for people with dementia in line with the needs identified from these assessments and with the recommendations arising from the joint review. This should include a process to allow the knowledge gained by experienced carers to be shared with new carers.

11.7 Section 9 recognised the added stress that admission to hospital can bring, both for the patient and for carers. DHSSPS, in partnership with the Carers' Strategy Implementation Group, developed a guide for carers informing them about the process of discharging a patient from hospital or intermediate care setting, the decisions that may have to be made and what they can expect to happen during the discharge process. A guide was also developed to help HSC Trust managers and

policy makers develop policy and practice in identifying and involving carers in planning for a patient's discharge from hospital and intermediate care. The guidance was issued to the HSC Board and Trusts in September 2010³⁴.

Actions

Trusts will develop policy and practice in identifying and involving carers in planning for a patient's discharge from hospital and intermediate care.

Summary

- 11.8 The introduction of the carer assessment with the NISAT arrangements is an important step forward in ensuring that carers' needs are taken into account. Family members and other carers may have to make decisions on behalf of the person with dementia; these may be important decisions about their care or about their finances.
- 11.9 It is intended that decision making for those unable to make their own decisions will in future be provided within a new legal framework, which is outlined in the next section.

³⁴ Carer and Discharge Guidance: Guides for Carers, Staff and Managers/Policy Makers, DHSSPS 2010

Section 12: Legislative Change

- 12.1 The Bamford review's recommendations for changes to mental health legislation and for the introduction of new mental capacity legislation, based on a common set of principles and contained in a single legislative framework, have been accepted by the NI Executive. It has been agreed that the legislative framework will be delivered through a single Act encompassing mental capacity and mental health provisions. The aim of the proposed legislation is to promote the dignity and human rights of those who lack mental capacity to make decisions for themselves. The new Bill will replace the Mental Health (NI) Order 1986.
- 12.2 A major element of this legislative reform will be to embed a set of principles in the legislation. The lead principle will be Autonomy, which involves the legal presumption of capacity, respecting a person's right to decide and act on their decisions regarding treatment, care, welfare, finances and/or assets. Where decision-making is impaired, the legislation will provide for substitute decision-making and for additional powers and protections to be put in place, which will act to ensure the best interests of the individual.

Impact of the proposed Legislation on those with Dementia

- 12.3 Those with dementia may fall within the remit of the Bill, depending on the extent of their condition. The new legislation will apply where a person lacks the mental capacity to make a specific decision for themselves. The scope of the legislation will cover a wide range of decisions, including financial decisions such as the making of wills and investments but also the spending of cash on behalf of the person, care and welfare decisions such as where a person will live, and medical treatment decisions. However, before the provisions of the proposed

legislation are engaged it will be necessary to show that the person lacks the capacity to make a decision themselves.

- 12.4 The legislation will contain a test of capacity which will require that there must exist an impairment or disturbance in the functioning of the mind or brain (diagnostic) and that as a consequence the person is unable to understand, retain or use or weigh the information needed to make the decision or to communicate the decision (functional). A person will have to be assisted in understanding and the person will only have to retain the information long enough to make the decision. Also, assumptions cannot be made that, because of a particular condition or the person's age, an individual is unable to make all decisions in their life: the test is decision-specific.
- 12.5 The legislation will provide for a number of substitute decision-making arrangements, such as lasting powers of attorney, court-appointed deputies and, where these arrangements do not exist, a hierarchical tier of authorised interventions, where the safeguards provided will increase in proportion to the seriousness of the intervention. In all cases of substitute decision-making those making the decisions will be required to act in the best interests of the person affected. Providing for lasting powers of attorney will be particularly important in respect of those with dementia as they envisage situations where the person, while retaining capacity, makes their own arrangements for future decision-making for a time when that capacity is lost. Lasting powers of attorney will replace the current system of enduring powers of attorney widening the remit from financial decisions to also include welfare and health decisions.
- 12.6 Advance decisions can already be made through the common law and the Department proposes that this should remain the position, but the legislation will provide as part of the best interests assessment that the past and present views of a person are taken into account when decisions are being made on behalf of the person lacking capacity.

You need to be doing it now, the stage when you are early diagnosis and you can still get consent; we left it too late.

Comment from Listening Well report

- 12.7 The proposed legislation will also provide statutory safeguards for those incapable but compliant individuals who require to be deprived of their liberty for their care and protection. The safeguards envisaged will require those depriving the person of their liberty to act in the best interests of the person, and make provision for the person or their representative to have the right to go to a judicial forum to challenge the basis of the deprivation of liberty. Interim guidance to promote best practice in this area was published by the DHSSPS in October 2010³⁵.
- 12.8 In addition, the single Bill will provide a right of independent advocacy to those affected by the legislation in circumstances where a serious intervention is required but the person lacking capacity or their nominated person objects to the intervention or where the person is being deprived of their liberty. A key function of the advocate will be to ascertain the views of the person affected and ensure decision-makers are aware of those views but also to advise the person lacking capacity and their nominated person of any right of review they may have..

Action

Subject to Executive approval, the DHSSPS will develop new Mental Capacity Bill for introduction in to the Assembly in 2012/13.

The Department will be required to publish a Code of Practice in relation to the provisions of the Bill and the Department proposes to have that Code available as soon after the Bill is enacted as possible.

³⁵ Deprivation of Liberty Safeguards (DOLS) – Interim Guidance; Circular Letter HSC/MHDP–MHU 1/10 DHSSPS (2010)

Summary

12.9 This section summarises the proposals for new legislation and how these might impact on people with dementia and their families. The next section outlines how research in NI can best be linked to the world- wide research into the causes of dementia, with a view to finding a cure, and into how best to care for those with dementia.

Section 13: Promoting Research

- 13.1 Research on dementia is needed in the three main areas - *Cause*, *Cure* and *Care*. Dementia has a world-wide impact, which calls for a co-ordinated approach to research, pooling talents and resources, where appropriate. The aim is to understand the biological basis of dementia, possible ways of preventing neurodegeneration, the psychological and social supports that are most effective and ensuring that potential interventions are trialled and made available to patients as quickly as possible.
- 13.2 Funding for clinical and social research to be undertaken in Northern Ireland is available from many sources including local and UK Government, a wide range of charities, the European Commission, and others such as the US National Institutes of Health.
- 13.3 In the UK, a Medical Research Council (MRC) review of research needs for neurodegenerative diseases concluded that the immediate priority is basic research. A need to increase the number of scientists and clinicians trained in relevant research methodologies was also recognised, leading to a new £30m initiative to fund research projects. MRC is also boosting its support for research on neurodegeneration by supporting a UK brain bank.
- 13.4 The MRC's review also recognised that there is currently limited funding of clinical trials in neurodegenerative diseases. Many of the current trials involve drugs already on the market to see in what new ways they might be used to benefit patients.
- 13.5 Across the UK, there is agreement in place that, for health related research, basic research is funded through MRC, with the Health Departments of each UK country providing funds aimed at translating research into benefits for patients. Currently in NI, HSC Research and

Development (R&D) is enhancing opportunities for research to lead to improved patient outcomes. Its portfolio of funded projects is now more focussed on clinical research and trials. The major vehicle for supporting clinical trials is the Northern Ireland Clinical Research Network (NICRN).

- 13.6 The NICRN provides support for staff to carry out studies and trials on new potential interventions or diagnostic technologies. For NICRN, network themes are in place for nine disease areas, of which one is dementia.
- 13.7 The very small NI academic base and limited resources for health-related research require our local researchers to collaborate with the substantial groups from elsewhere in the UK or internationally for basic research. An example of a recent successful international collaboration is work on associations between genes and Alzheimer's Disease that was published in 2009. Billed as the largest breakthrough in Alzheimer's genetics for 16 years, QUB researchers contributed to the important findings.
- 13.8 There is scope to build health and social care research locally in a multi-disciplinary, multi-professional way with strong involvement of patients, carers and organisations that represent and support them. Research is a key strand of the work programme of the Dementia Services Development Centre's Northern Ireland Office which, through its links with the University of Stirling, carries out multidisciplinary, policy and practice relevant social scientific research with particular emphasis on the rights of people with dementia and their unpaid carers.
- 13.9 The University of Ulster launched its Centre for Mental Health and Wellbeing in 2011. Education and research on mental health, including dementia, will be the Centre's major initial focus. The Centre will be multi-disciplinary and multi-professional, building upon an excellent

research base in Nursing and Psychology in addition to fundamental Biomedical Sciences. Much of the research is done in collaboration with partners worldwide.

13.10 In order to grow the local research effort on dementia, access to and effective use of expertise and funding are both required. These can best be achieved through:

- strategic interactions among researchers and clinical colleagues to ensure that research is informed by clinical needs and research findings are translated into improved outcomes for patients;
- collaboration with substantial dementia research groups based elsewhere in the UK, on the island of Ireland (e.g. facilitated by organisations such as the Centre for Ageing Research and Development in Ireland (CARDI)) and internationally;
- continued support for NICRN-based clinical trials that involve people with dementia, with the full support of HSC Trusts being essential;
- support for multi-disciplinary, multi-professional research with strong involvement of HSC Trusts, patients, carers and organisations that represent and support them.

13.11 The proposed Mental Capacity Bill will also contain additional protections for those who lack capacity because of dementia and who are involved in a research project.

Actions

HSC R&D will continue to support NICRN (Dementia).

HSC R&D will continue to support researchers to prepare high quality applications for research on dementia or related neurodegenerative diseases for National Institutes of Health peer review via the US-Ireland R&D Partnership.

HSC R&D will support researchers making high quality applications on dementia or related neurodegenerative diseases for major funding via UK Research Councils, EU Framework programme, major charities etc.

HSC R&D will support initiatives aimed at building inter-disciplinary and/or inter-professional research in health and/or social care for people with dementia or related neurodegenerative diseases. Ideally such initiatives should have a strong element of patient and/or public involvement.

Summary

13.12 Research into dementia requires long-term collaboration with a wide range of partners. This strategy has however identified a number of actions which are specific to NI to improve life for people with dementia. Section 14 outlines how these actions will be co-ordinated and considers the resources required. The tables in Section 15 summarise the actions and identify lead responsibility and timescales for completion.

Section 14: Implementing the Strategy

- 14.1 In their role in commissioning health and social care services and promoting inter-sectoral work to support health improvement, the HSC Board and the PHA will jointly co-ordinate and take forward work on making this strategy a reality.
- 14.2 Recognising that dementia services were included as part of the Bamford review of mental health services for older people, there are structures already put in place to drive forward the Bamford agenda, including a Task Force led by HSC Board and PHA to take forward work in the health and social care sector. The growing prevalence of dementia and the scale of the work involved in implementing this strategy, however, calls for work on this strategy to be driven forward on its own merits, separate from the wider Bamford agenda.
- 14.3 It is proposed, therefore, that a jointly led HSC Board/ PHA regional group with representation from providers, both statutory and non-statutory, people with dementia, those who care for them and organisations representing them will oversee this work. Responsibility for leading this group should lie with those responsible for care for older people rather than for mental health care, but with appropriate involvement of mental health interests. The group will report to the DHSSPS on progress against the actions on a 6-monthly basis.
- 14.4 The evaluation of the current three year pilot of the Dementia Services Development Centre in Northern Ireland, which seeks to support service improvement and promotion of best practice through provision of dementia-specific training, education, consultancy, information and research services, will inform decisions about the need for and focus of such a Centre on an ongoing basis to help to drive change and enhance services.

14.5 The actions proposed in this strategy have essential links to a number of other strategies and work streams, for example, on support for carers, living with long term conditions, end of life care, implementation of NICE guidance, the introduction of the Northern Ireland Single Assessment Tool and the anticipated development of a service framework for older people. The HSC Board/ PHA regional group leading on this strategy will therefore need to forge effective links with the bodies and groups taking forward work in other relevant areas such as those identified above.

Resourcing the Strategy

14.6 There are significant resource requirements to take some of these actions forward, but there are also opportunities to release and re-direct resources. Some of the actions in the Action Plan are being taken forward in the context of other strategies and work streams, as outlined at paragraph 14.5. Others can be accommodated through adapting existing work, for example, public campaigns already promote healthy lifestyles to prevent conditions other than dementia. There is also substantial investment in providing appropriate care and support to people in their own homes and this will continue.

14.7 Over and above this, actions proposed in this strategy which require significant additional resources are:

- improving memory services to provide access to early diagnosis and support;
- improving access to supported living and to assistive technologies;
- improving access to intermediate care;
- improving care in acute hospitals;
- improving care in care homes;
- improving staff knowledge and skills across all sectors.

14.8 There are, however, opportunities to “invest to save”. Early diagnosis and better support to individuals and families, including access to improved memory services, respite and intermediate care, could prevent or delay admissions to hospital or care homes in the longer term. A 10% reduction in use of care home places in Northern Ireland could release an estimated £10m of public expenditure. Better care in acute hospitals should reduce lengths of stay and promote discharge to the person’s own home rather than a care home.

Summary

14.9 In their commissioning decisions over coming years, the HSC Board and the PHA, in partnership with other relevant agencies, will take forward work on the actions outlined in Section 15 of this strategy to improve services of people with dementia. These decisions will take into account the priorities for improvement identified in this section as well as the opportunities to “invest to save”.

Section 15: The Action Plan

The Action Plan

15.1 The actions proposed in the strategy are summarised in the table below, indicating lead responsibility for taking the action forward and the timescale proposed for the action. Each action is also linked to one or more of the values underpinning this strategy; these values are:

1. Dignity & respect
2. Autonomy
3. Justice & equality
4. Safe, effective person-centred care
5. Care for carers
6. Skills for staff

Action Plan

Reducing the Risk or Delaying the Onset of Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
1. Continue to promote healthy lifestyles and avoidance of risk factors to the general population for the prevention of heart disease, stroke, mental illness etc.	Public Health Agency	Ongoing	1,2
2. Consider feasibility of developing initiatives that may reduce serious head injuries	Public Health Agency	By June 2012	1,2
3. 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 primary prevention for middle aged and older people.	HSC Board and Public Health Agency in collaboration with LCGs	Ongoing	1,2
4. 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.	HSC Board and Public Health Agency in collaboration with LCGs	Ongoing	1,2
5. Consideration will be given to the addition of primary prevention targets for dementia and to the further development of secondary prevention targets to the Dementia Indicator to the Quality and Outcomes Framework	HSC Board and Public Health Agency in collaboration with LCGs	Ongoing	1,2
6. 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.	HSC Board and Public Health Agency	Ongoing	1,2

Action Plan

Reducing the Risk or Delaying the Onset of Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
7. Develop clear protocols for primary and secondary care professionals regarding appropriateness of referral to genetic services for patients likely to have a genetic basis to their dementia and their unaffected relatives.	HSC Board and Public Health Agency	By June 2012	1,2

Action Plan

Raising Awareness

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
8. Draw up and lead on a plan to: <ul style="list-style-type: none"> • address stigma; • raise public awareness about what can be done to reduce the risk of or delay dementia; and • raise public awareness of the signs and symptoms of dementia and about the benefits of seeking help early 	Public Health Agency	Have plan with timescales agreed by September 2012	1,2, 3
9. Work in partnership with other public bodies and with local community and voluntary sector bodies to challenge stigma relating to dementia and to encourage better understanding of the condition and its signs and symptoms among those providing services to the public	DHSSPS, HSC Board and Public Health Agency with HSC Trusts and other agencies	Ongoing	1,2,3
10. Co-ordinate a training and development plan across primary, community and secondary care, in statutory and non-statutory sectors, to improve knowledge and skills in providing care to people with dementia, including the needs of informal carers	DHSSPS HR Directorate, HSC Board, Public Health Agency and HSC Trusts	Plan by September 2012 and ongoing delivery	3,4,5,6
11. Supplement the GP information pack produced by the Dementia Services Development Centre with information on local services available	HSC Trusts	By June 2012	4,5,6

Action Plan

Promoting Early Assessment and Diagnosis

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
12. Agree on a minimum range of services that a memory service should provide, regardless of whether the service is community- or hospital-based	HSC Board in collaboration with the Public Health Agency, LCGs and Trusts	By June 2012	3,4
13. Ensure that memory services meet the principles outlined in Table 4 and that the agreed minimum services are available to people in their area.	HSC Trusts	By March 2013	3,4
14. Agree on and establish a regional tertiary service to be led by one Trust with agreed referral criteria from local memory services.	HSC Trusts in collaboration with HSC Board and Public Health Agency	By March 2013	3,4
15. Draw up criteria and clear protocols for referral from GP practices to the memory service	HSC Board in collaboration with the Public Health Agency and LCGs	By March 2013	3,4,6
16. Ensure that memory services provide advice and information services and are able to signpost to other relevant advice and information services.	HSC Trusts	By March 2013	3,4,5,6
17. Conduct a review of the effectiveness of memory services	Regulation and Quality Improvement Authority	By December 2014	3,4

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
18. Develop a service specification to inform commissioning for dementia care to include: <ul style="list-style-type: none"> • information provision to individuals, families and carers; • therapeutic interventions and medicines management in the statutory and non-statutory sectors; • a range of provision to preserve people's functioning and prevent decline; • a range of both traditional and innovative short break provision to meet the needs of people with dementia and their carers; • environmental standards for all new facilities; • supported housing; • memory services provision to enhance early diagnosis and an integrated pathway approach; • tertiary service provision. 	HSC Board in collaboration with the Public Health Agency and other relevant organisations	By September 2012	3,4,5
19. Work together with LCGs on a programme to improve understanding of the issues involved in commissioning dementia services	HSC Board and PHA	By September 2012	3,4,5
20. Finalise the draft Policy for Developing Advocacy Services – A Guide for Commissioners and monitor its implementation	DHSSPS	By January 2012 Monitoring ongoing thereafter	1,2,3
21. Ensure that all people with a diagnosis of dementia seeking services have a care plan drawn up and reviewed in line with the Northern Ireland Single Assessment Tool (NISAT)	HSC Trusts	From December 2011	2,4

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
22. Conduct an audit of the interventions available for dementia care across all settings, including nursing and residential care	HSC Board in collaboration with the Public Health Agency	By December 2013	3,4,5
23. Carry out a programme of environmental assessment of existing facilities used by people with dementia and draw up a prioritised improvement plan for action as resources permit	HSC Board in collaboration with other organisations as above	Ongoing	3,4
24. Commission a literature review on the cost effectiveness of assistive technologies in supporting people with dementia.	Public Health Agency	By September 2012	2,4,5
25. Use above review to inform a regional procurement approach by Trusts, in collaboration with housing providers, the European Centre for Connected Health and Dementia Services Development Centre's Northern Ireland Office	HSC Trusts in collaboration with others	From April 2013	2,4,5
26. Continue to work with DSD and the NI Housing Executive on supported housing matters and agree on priorities in line with available capital and revenue resources	DHSSPS and the HSC Board	Ongoing	2,4,5
27. Ensure that appropriate care pathways are developed to ensure that people with dementia have access to services equipped to respond to crisis, including intermediate care	HSC Trusts in collaboration with HSC Board, Public Health Agency and LCGs	By September 2012	4,5
28. Review current hospital bed provision for dementia assessment and harmonise provision across Trusts, with an emphasis on developing assessment services in the community.	HSC Board in collaboration with HSC Trusts and Public Health Agency	By December 2012	4,5

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
29. Develop palliative and end of life care services for people with dementia within the framework of the palliative and end of life care strategy	HSC Trusts	In line with timescales for palliative care strategy	4,5
30. Develop a regional care pathway for younger people with dementia, including access to the regional tertiary memory service	HSC Trusts	By September 2012	3,4,5
31. Ensure that people with a learning disability and dementia are supported by learning disability services, with access to the full range of specialist dementia services to meet individual needs	HSC Trusts	By September 2012	3,4,5
32. Ensure that specialist dementia diagnostic and support services provide the necessary reasonable adjustments to enable full access by people with learning disabilities	HSC Trusts	By September 2012	3,4,5
33. Ensure that an individual care plan is drawn up for each person with dementia admitted to acute hospital care, focusing on the dementia-specific supports necessary to ensure appropriate care in and timely discharge from hospital	HSC Trusts	By March 2012	3,4,5
34. Work with HSC Trusts to enhance knowledge and skills on the care of individuals with dementia, when admitted to acute wards	Dementia Services Development Centre (Northern Ireland) with Trusts	During 2011/12/13	4,5,6

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
35. Develop standards for commissioning dementia care in care homes (see action 18)	HSC Board, in collaboration with the PHA and Trusts	By September 2012	3,4,5

Action Plan

Supporting Carers

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
36. Implement the NISAT carer's assessment tool in respect of those caring for people with dementia	HSC Trusts	Ongoing	5
37. Develop support, including practical, educational and, where appropriate, psychological support to those caring for people with dementia in line with the needs identified from these assessments and with the recommendations arising from the joint DSD/DHSSPS review of support for carers, including a process to allow the knowledge gained by experienced carers to be shared with new carers.	HSC Trusts	In line with timescales for work arising from joint review	5
38. Develop policy and practice in identifying and involving carers in planning for a patient's discharge from hospital and intermediate care	HSC Trusts	By September 2012	5

Action Plan

Legislation

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
39. Develop and ensure introduction of new Mental Capacity legislation to include a right to independent advocacy where serious intervention is required and the person lacks capacity	DHSSPS	Enactment during 2013/14 Assembly session	1,2,3
40. Publish a Code of Practice in relation to the provisions of the new legislation	DHSSPS	As soon as possible after legislation is enacted	1,2,3

Action Plan

Research

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
41. Continue to support NICRN (Dementia)	Public Health Agency in collaboration with universities and non-statutory sector	Ongoing	1,4
42. Continue to support researchers to prepare high quality applications for research on dementia or related neurodegenerative diseases for National Institutes of Health peer review via the US-Ireland R&D Partnership	Public Health Agency in collaboration with universities and non-statutory sector	At least one successful application in 2011	1,4
43. Support researchers making high quality applications on dementia or related neurodegenerative diseases for major funding	Public Health Agency in collaboration with universities and non-statutory sector	Ongoing as initiatives arise through major research funders, e.g. MRC, following its review of Mental Health & Wellbeing	1,4
44. Support initiatives aimed at building inter-disciplinary and/or inter-professional research in health and/or social care for people with dementia or related neurodegenerative diseases. Ideally such initiatives should have a strong element of patient and/or public involvement	Public Health Agency in collaboration with universities and non-statutory sector	A programme of commissioned research in mental health, including dementia, with the first projects commissioned in 2011	1,4

ABBREVIATIONS

CRF	Clinical Research Facility
CRSC	Clinical Research Support Centre
DHSSPS	Department of Health, Social Services & Public Safety
DoH	Department of Health (England)
DSD	Department for Social Development
HSC	Health and Social Care
MRC	Medical Research Council
NICE	National Institute for Health and Clinical Excellence
NICRN	Northern Ireland Clinical Research Network
NIH	National Institute of Health
NISAT	Northern Ireland Single Assessment Tool
PHA	Public Health Agency
PSNI	Police Service of Northern Ireland
QOF	Quality and Outcomes Framework (GP contract)
QUB	Queen's University of Belfast
R&D	Research and Development
RQIA	Regulation and Quality Improvement Authority
SCIE	Social Care Institute for Excellence

THE PROGRESSION OF DEMENTIA

(Source: Alzheimer's Society <http://www.alzheimers.org.uk/factsheet/458>)

Each person experiences dementia in their own way, but it can be helpful to think of the way it progresses as a series of stages. This section describes briefly how other forms of dementia progress.

Alzheimer's disease

Alzheimer's disease is a progressive illness. This means that the structure and chemistry of the brain become increasingly damaged over time. The person's ability to remember, understand, communicate and reason will gradually decline. Looking at Alzheimer's disease as a series of three stages can be a useful way of understanding the changes that occur over time. But it is important to realise that this view of Alzheimer's can only provide a rough guide to the course of the disease. This is because:

- Some symptoms may appear earlier or later than indicated here, or not at all.
- The stages may overlap - the person may need help with one task, but may be able to manage another activity on their own.
- Some symptoms, such as walking about, may appear at one stage and then vanish, while others such as memory loss will worsen over time.

The way that a person experiences Alzheimer's disease will depend on many factors, including their physical make-up, their emotional resilience and what support they can rely on.

Early stage

Alzheimer's disease usually begins gradually with very minor changes in the person's abilities or behaviour. At the time, such signs are often mistakenly attributed to stress or bereavement or, in older people, to the normal process of ageing. It is

often only when looking back that we realise that these signs were probably the beginnings of the dementia.

Loss of memory for recent events is a common early sign. Someone with Alzheimer's may:

- forget about recent conversations or events
- repeat themselves
- become slower at grasping new ideas, or lose the thread of what is being said
- sometimes become confused
- show poor judgement, or find it harder to make decisions
- lose interest in other people or activities
- develop a readiness to blame others for taking mislaid items
- become unwilling to try out new things or adapt to change.

If you are caring for someone with Alzheimer's disease, there's a lot you can do in the early stages to help the person you are caring for maintain their independence. It may be tempting to do things for them, but they are more likely to retain their sense of self-worth if they are given the chance to do things for themselves, with support if necessary.

The person may also become anxious and agitated. They may experience distress over their failure to manage tasks, and may need some reassurance. If this is the case, try to talk to them, and give them as much emotional support as you can.

Middle stage

As Alzheimer's disease progresses, the changes become more marked. The person will need more support to help them manage their day-to-day living. They may need frequent reminders or help to eat, wash, dress and use the toilet. They are likely to become increasingly forgetful - particularly of names - and may sometimes repeat the same question or phrase over and over because of the decline in their short-term memory. They may also fail to recognise people or confuse them with others.

Some people at this stage become very easily upset, angry or aggressive - perhaps because they are feeling frustrated - or they may lose their confidence and become very clingy. Other symptoms may include:

- becoming confused about where they are, or wandering off and becoming lost
- becoming muddled about time and getting up at night because they are mixing up night and day
- putting themselves or others at risk through their forgetfulness - for example, by not lighting the gas on the cooker
- behaving in ways that may seem unusual, such as going outside in their nightclothes
- experiencing difficulty with perception, and in some cases hallucinations.

Late stage

At this stage, the person with Alzheimer's will need even more help, and will gradually become totally dependent on others for nursing care. Loss of memory may become very pronounced, with the person unable to recognise familiar objects or surroundings or even those closest to them, although there may be sudden flashes of recognition.

The person may also become increasingly frail. They may start to shuffle or walk unsteadily, eventually becoming confined to bed or a wheelchair. Other symptoms may include:

- difficulty in eating and, sometimes, swallowing
- considerable weight loss - although some people eat too much, and put on weight
- incontinence, losing control of their bladder and sometimes their bowels as well
- gradual loss of speech, though they may repeat a few words or cry out from time to time.

The person may become restless, sometimes seeming to be searching for someone or something. They may become distressed or aggressive - especially if they feel threatened in some way. Angry outbursts may occur during close personal care, usually because the person does not understand what is happening. Those caring for the person should try not to take this personally.

Although the person may seem to have little understanding of speech, and may not recognise those around them, they may still respond to affection and to being talked to in a calm soothing voice, or they may enjoy scents, music, or stroking a pet.

Vascular dementia

In vascular dementia, which is commonly caused by a stroke or a series of small strokes, brain cells are deprived of oxygen and die. This can occur in distinct parts of the brain, leaving other areas relatively unaffected.

Some people with vascular dementia find that symptoms remain steady for a time and then suddenly decline as the result of another stroke. Others experience a more gradual decline.

It is sometimes difficult to determine whether people have Alzheimer's or vascular dementia. It is also possible to be affected by both.

Fronto-temporal dementia (including Pick's disease)

This type of dementia is caused by damage to the frontal and/or temporal lobes of the brain. These are the areas responsible for our behaviour, our emotional responses and our language skills.

During the early stages of fronto-temporal dementia, memory for recent events may be unaffected. However, there may be other changes. For example, the disease may cause some people to appear uncharacteristically selfish and unfeeling. They may behave rudely, or may seem more easily distracted. Other symptoms may include loss of inhibition, ritualised behaviour and a liking for sweet foods. In a small number of cases, a person's first problems may be with recalling the names of objects and

comprehending words (semantic dementia) or with producing fluent speech (progressive non-fluent aphasia).

In later stages the symptoms are more similar to those experienced in Alzheimer's disease.

Dementia with Lewy bodies

Dementia with Lewy bodies gets its name from microscopic deposits that are found in the brain after death. These cause the degeneration and eventual death of nerve cells in the brain.

Half or more of those affected by dementia with Lewy bodies also develop signs and symptoms of Parkinson's disease, such as slowness of movement, stiffness and tremor. They may also have difficulty in judging distances, and are more prone to falls. People with this type of dementia also commonly experience visual hallucinations. One feature of this type of dementia that often puzzles those around them is that the abilities of the affected person may fluctuate from day to day, or even during the course of a single day.

In the later stages, the symptoms are often very similar to those experienced in Alzheimer's disease.

Assistive technology

(Source: Alzheimer's Society <http://www.alzheimers.org.uk/factsheet/437>)

The term 'assistive technology' refers to 'any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed' (Royal Commission on Long Term Care 1999). This includes equipment and devices to help people who have problems with:

- speaking
- hearing
- eyesight
- moving about
- memory
- cognition (thought processes and understanding).

Assistive technology ranges from very simple tools, such as calendar clocks and touch lamps, to high-tech solutions such as satellite navigation systems to help find someone who has got lost.

What are the benefits?

Assistive technology can help by:

- increasing independence and choice, both for the person with dementia and those around them
- reducing the risk of accidents in and around the home
- reducing avoidable entry into residential and hospital care
- reducing the stress on carers, improving their quality of life, and that of the person with dementia.

Finding the right solution

Selecting the right device is not always easy. Sometimes it may be that a non-technological solution is more appropriate. Different people react differently to different products. One person might find a simple recorded message that plays when they open the front door, reminding them to take their keys helpful, while another person might find this confusing. Before you make a decision, seek as much advice as possible. Whenever you can, involve social services and the person's occupational therapist or GP in your decision, to ensure a tailored solution. If the assistive technology does not meet the individual needs and preferences of the person with dementia, it may be ineffective or even cause distress.

What may be useful for one person at a particular stage may not be appropriate for another. Equipment is not always the answer. It may be enough to make small changes in the way that daily activities are organised.

Terms of Reference

To develop a strategy for improving services for people with dementia and for their carers in Northern Ireland, in line with the recommendations for improving dementia services made in the Bamford Review's paper 'Living Fuller Lives', which addresses the projected increase in dementia and the anticipated increased in demand on the health and social care system, in the context of the Executive's Programme for Government, and in ways which are consistent the Department's overall modernisation agenda.

The Strategy will link to other policies, frameworks and strategic documents and will seek to:

- Promote systems approaches to prevention, assessment, early diagnosis, treatment, care and support for individuals, their families and carers;
- Highlight current service provision, its capacity and future demand, recognising the importance of engagement with service users and carers as part of this process;
- Improve the care pathway through service redesign, a focus on high standards of care and performance improvement;
- Improve public awareness and promote earlier recognition, access, evidence based interventions and support for service users, families and carers;
- Recognise the importance of effective multidisciplinary and interagency working in order to deliver services to meet need;
- Promote research into dementia; its causes, treatment and care; and
- Develop an Action Plan, drawing on a substantial local, national and international evidence base, to improve the lives of those who have dementia and to inform future strategic direction for dementia services.

MEMBERSHIP OF STEERING GROUP

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Heather Cousins	Housing Division, DSD
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Brendan Forde	Commissioning Officer, Allied Health Professions, Public Health Agency
Joan Hamilton	Service User
Geoff Huggins	Head of Mental Health Division, Scottish Executive
Christine Jendoubi	Director of Primary and Community Care, DHSSPS
Molly Kane	Lead Regional Nurse, Public Health Agency
Claire Keating	Northern Ireland Director, Alzheimer's Society (until 1 st July 2010)
Deidre Blakely	Acting Northern Ireland Director, Alzheimer's Society (from 1 st July 2010)
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EXTERNAL REFEREES

NAME	TITLE
Professor June Andrews	Director of the Dementia Services Development Centre, University of Stirling
Professor Sube Banerjee	Professor of Mental Health and Ageing, The Institute of Psychiatry, King's College London

GLOSSARY OF TERMS

Acute Services

Health care and treatment provided mainly in hospitals.

Allied Health Professionals

Groups of professionals working in the health and social care services including physiotherapists, occupational therapists, speech therapists, chiropodists/podiatrists, dieticians, radiographers and orthoptists.

Care Home

A residential home which provides either short or long term accommodation with meals and personal care (e.g. help with washing and eating). Some care homes, known as nursing homes, also have registered nurses who provide nursing care for more complex health needs.

Care Plan

The outcome of a needs assessment. A description of what an individual needs and how these needs will be met.

Carer

Carers are people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, illness or disability.

Carer's Assessment

An assessment, carried out by a social worker or a member of social services, which enables an unpaid carer to discuss the help they need to care, to maintain their own health and to balance caring with their life, work and family commitments.

Commissioning

The process of identifying local health and social care needs, making agreements with service providers to deliver services to meet these needs, and monitoring outcomes. The process of commissioning seeks to improve quality of life and health outcomes for patients and carers.

Community health and care services

Services provided outside the hospital setting by health and social care professionals.

Direct payments

Direct Payments have been available since 1996 and aim to promote independence by giving people flexibility, choice and control over the purchase and delivery of services that support them. Individuals can opt to purchase services tailored to suit them by means of a Direct Payment from the HSC Trust.

District/Community Nurse

District/Community nurses visit people in their own homes or in residential care homes, providing care for patients and supporting family members. They work with patients to enable them to care for themselves or with family members and carers supporting them in caring their responsibilities.

Domiciliary Care

These services provide personal care for people living in their own homes. The needs of people using the services may vary greatly, but packages of care are designed to meet individual circumstances.

End of Life

A period of time during which a person's condition is actively deteriorating to the point where death is expected.

End of Life Care

The emphasis on end of life care focuses on helping all those with advanced progressive and incurable conditions to live as well as possible until they die. It enables the palliative care needs of both patient and family to be identified and met throughout the last phases of life and into bereavement.

Health and Social Care (HSC)

Hospital services, family and community health services and personal social services.

Health and Social Care Providers

Organisations (including public, independent and voluntary/community) which provide health and/or social care services, for example Health and Social Care Trusts, hospices, voluntary and community organisations.

Holistic Care

Comprehensive care that addresses the social, psychological, emotional, physical and spiritual needs of the individual.

Key Worker

A named member of a multi-disciplinary team with particular responsibility for co-ordinating both communication and the provision of care to the patient, their family and carers. The key worker undertakes a pivotal role in liaising between all parties involved in a patient's care to ensure that this is planned and provided in a streamlined way.

Multi-disciplinary Team

A group of people from different disciplines who work together to provide and/or improve care for patients with a particular condition. The composition of multi-disciplinary teams will include people from various disciplines (both healthcare and non-healthcare).

NI Single Assessment Tool (NISAT)

A system designed to capture the information required for holistic, person-centred assessment of the health and social care needs of the older person. Use of NISAT will standardise and streamline assessment and care planning processes.

Out-of-Hours

The out-of-hours period is usually 6.30pm to 8am on weekdays and all weekends and bank holidays. Under the new General Medical Services contract (2004), GPs can choose not to provide 24-hour care for their patients. During this time, local commissioners are responsible for the provision of GP services for local people.

Palliative Care

The active, holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.

Prevalence

Prevalence is defined as the proportion of people in a defined population that has the disease at a defined time point or period. It is usually quoted as a percentage. In the field of dementia, prevalence is often expressed as proportion of people in different age groups with dementia.

Primary Care

Family and community health services and major components of social care which are delivered outside the hospital setting and which an individual can access on his/her own behalf. Primary care will usually be a person's first point of contact with the HSC (e.g. GPs, dentists).

Priorities for Action (PfA)

Priorities for Action sets out the Minister's annual priorities and key challenges for the HSC. PfA provides the platform for monitoring the performance of the HSC in providing a continuously improving service.

Prognosis

The expected progression of a disease and its outcome for the individual.

Quality and Outcomes Framework (QoF)

A component of the General Medical Services contract for GPs. The QOF sets targets for GPs against evidence-based criteria covering a range of general and condition-specific indicators. Payments to practices are calculated on the basis of the extent to which these targets are met.

Rehabilitation

The process of restoration of skills by a person who has had an illness or injury so as to regain maximum self-sufficiency and function in a normal or as near normal manner as possible.

Respite Care

Provided on a short term and time limited basis, from a few hours per week to a number of weeks, respite care can either be planned or provided in response to an emergency. It can be done in a variety of ways, either outside or inside of the cared for person's home, and should be tailored to the needs of individual families and carers.

Secondary Care

Care often provided in a hospital or particular specialised centre. Secondary care may be accessed by a patient directly but is usually as a result of referral from primary care.

Service Framework

Evidence based standards to improve health and social care outcomes, reduce inequalities in health and social well-being and improve service access and delivery. Service frameworks set out standards of care that patients, clients, families and carers can expect to receive.

Social Care

Care services for vulnerable people, including those with special needs because of old age or physical or mental disability, or children in need of care and protection. Social care services which support people in their day to day lives to help them play a full part in society. Social care is usually provided in response to a needs assessment and can include services provided in a care home, the provision of a home help facility, meals on wheels and the provision of equipment.

Tertiary Care

Specialized consultative care, usually on referral from primary or secondary medical care personnel, by specialists working in a center that has personnel and facilities for special investigation and treatment.