

**IMPROVING DEMENTIA SERVICES IN NORTHERN
IRELAND**

A Regional Strategy

Consultation Paper

**Integrated Projects Unit
DHSSPS
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Ministerial Foreword

I am pleased to publish for consultation 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.

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.

I welcome consultation responses from all those affected by dementia – those who have the condition, their families and carers and those who provide services to them, whether in the statutory, community, voluntary or private sector. The general public will also wish to consider the content of this document.

An “easy read” version is also available.

Michael McGimpsey 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; under 1000 of these people have early onset dementia. In common with other parts of the developed world, as the population of Northern Ireland ages, dementia will increasingly become 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.

Dementia is not always preventable. Where possible, however, attempts should be made to prevent 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. People need 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 this work 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. Staff should have the right knowledge and skills to deliver effective care. A large share 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 early as possible. Early diagnosis allows people to receive treatment, care and support. Once diagnosed, people need to be supported to maintain as much independence as possible and to plan for the future.

Dementia has a fairly well defined progression, which calls for a staged approach to care and treatment, appropriate to the needs of the individual and their family. Care should promote and preserve independence and maintain the usual patterns of daily living and links with family and friends.

As far 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 are there because they need to be and that they receive appropriate care while 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. NI researchers and clinicians 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 cost to public services and to society in general.

Section 3 examines how the onset of dementia might be prevented or delayed by promoting healthier lifestyles and reducing risk factors such as high blood pressure and smoking. However, it is acknowledged that certain other risk factors cannot be modified.

Sections 4 and 5 consider what people with dementia have said is important to them and how support should therefore be designed for them.

Sections 6 and 7 look at what needs to be done to raise awareness of dementia, to encourage people to seek help as early as possible and to ensure that people who present with symptoms receive an appropriate initial assessment, diagnosis, information and support.

Sections 8-10 examine ways to improve the range of services used by people with dementia in order to promote people's 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 enhance protections for those who lack the capacity to make decisions for themselves.

Section 13 highlights the importance of research in this area and considers how NI researchers can contribute to what is a world-wide challenge.

Section 14 sets out how the strategy will be taken forward, recognising that there are links with other strategies. It considers the costs associated with 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 AN IMPORTANT CONDITION

Aim and Scope of the Dementia Strategy

1.1 Dementia is a 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 lives 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 aim is to produce a dementia strategy which will:-

- Promote a greater understanding of how dementia impacts on the lives of individuals, and how people can be supported to live with dignity and as valued members of our society;
- Raise public awareness on dementia and on how members of the public can take some measures to reduce the risk of developing dementia and potentially delay its onset;
- Share information on dementia to allow individuals, families and carers to make informed decisions, maximise independence and enhance daily living;
- Listen to the voice of those living with dementia and further develop health and social care commissioning and provision of dementia services to promote access to earlier diagnosis, and multidisciplinary assessment and support, 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 enhances the integration and skills of those who work in the statutory, community, voluntary and independent sectors.
- 1.3. The following paragraphs highlight the strategic context for development of this strategy, recognising that evidence on what is effective for the care of dementia changes over time and that much has been written at international, national and local levels on dementia. 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 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. Current work arising from this includes a recent consultation on proposals to establish a Commissioner for Older People to provide a 'strong independent voice' for older people; the outcome of that consultation is not yet known.
- 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 a series of recommendations in relation to services for people with dementia. These recommendations were intended to improve the identification, treatment and

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

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

care of people with dementia and to give greater support to their carers. The Bamford review envisaged 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 Much has been written on dementia care at international level, for example, in Canada, America, Europe and Australia. At national level, in England and Wales a national strategy “Living Well with Dementia”⁵ was published in February 2009. This strategy provides a framework within which local services can 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 apply to England and Wales only.
- 1.8 The Scottish Government have also published a consultation paper⁸ in 2009 and is currently formulating its own dementia strategy. In addition, the Scottish Intercollegiate Guidelines Network has produced guidance on the management of dementia⁹.
- 1.9 Clear strategic direction is essential for Northern Ireland, in order to improve services for people with dementia and for their carers. It is needed to provide appropriate support to those within our current population who have dementia and their carers. In addition, it has to recognise the 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

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

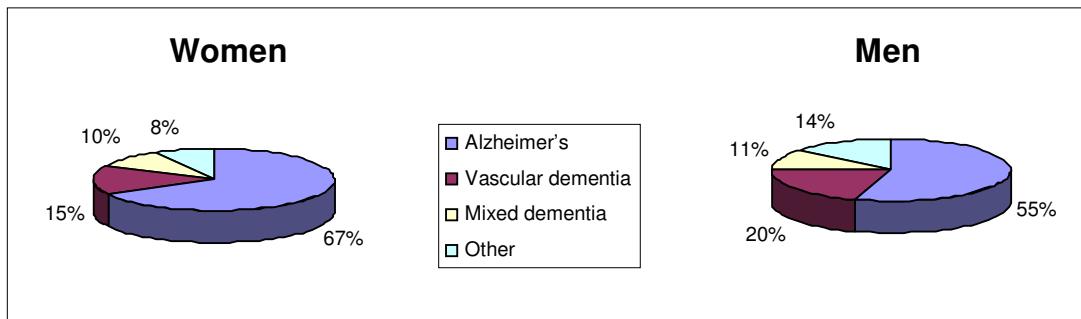
⁷ Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer’s disease (amended); Technology appraisal guidance 111, NICE 2009

⁸ The National Dialogue on Dementia: Dementia Strategy Consultation Paper; Scottish Government 2009

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

- 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. Vascular dementia is caused by a series of small strokes which interfere with the brain’s blood supply and whose cumulative effect can cause considerable problems for the person affected.
- 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, Huntington’s disease, and Down’s Syndrome.

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;

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

- disorientation;
- language and communication difficulties;
- changes in mood, behaviour, or personality;
- wandering behaviours; and
- hallucinations and delusions.

1.14 The above 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 maximise treatment and support which should be tailored to individual needs. Although dementia is a progressive condition, much can be done to enhance independence and active participation in society. Further information on the progression of dementia and on how aids, adaptations and technology can help people with dementia are given in Appendices 2 and 3.

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

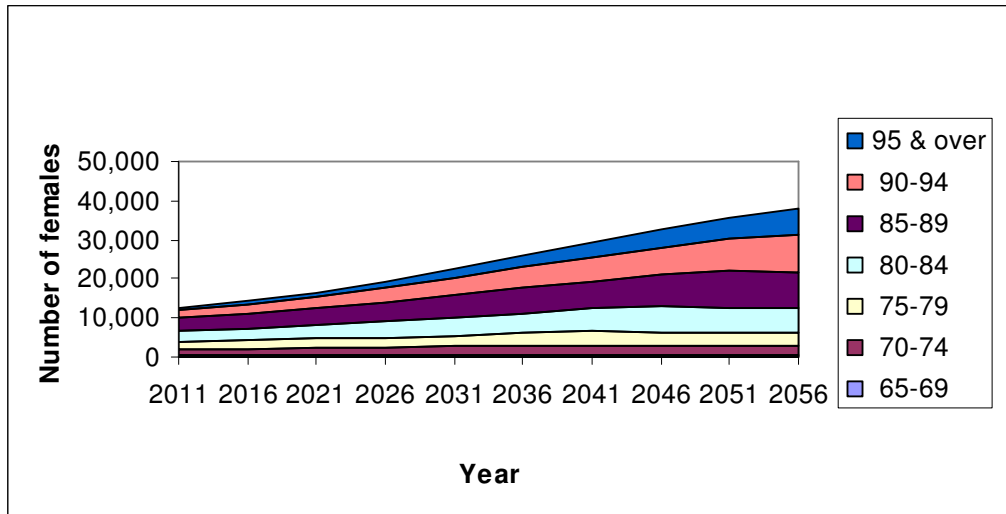
Facts and Figures

- 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 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 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 will be significant implications, both personal and public.
- 2.3 At present, it is estimated that in Northern Ireland there are 19,000 people are living with dementia; under 1000 of these people have early onset dementia¹¹.
- 2.4 An ageing population in Northern Ireland could see the numbers of people diagnosed with dementia going from the current estimate of 19,000 to 23,000 by 2017 and around 60,000 by 2051, bringing increasing pressures on families and carers, society and on those health and social care services which people with dementia might need to use.
- 2.5 In Northern Ireland, women tend to live longer than men. The average life expectancy for a woman is currently 81 years and for a man is 76 years. As dementia occurs more frequently in the older age groups and as women live longer than men, then women, as a group, have a higher prevalence of dementia than men. This is also reflected in population projections where it is

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

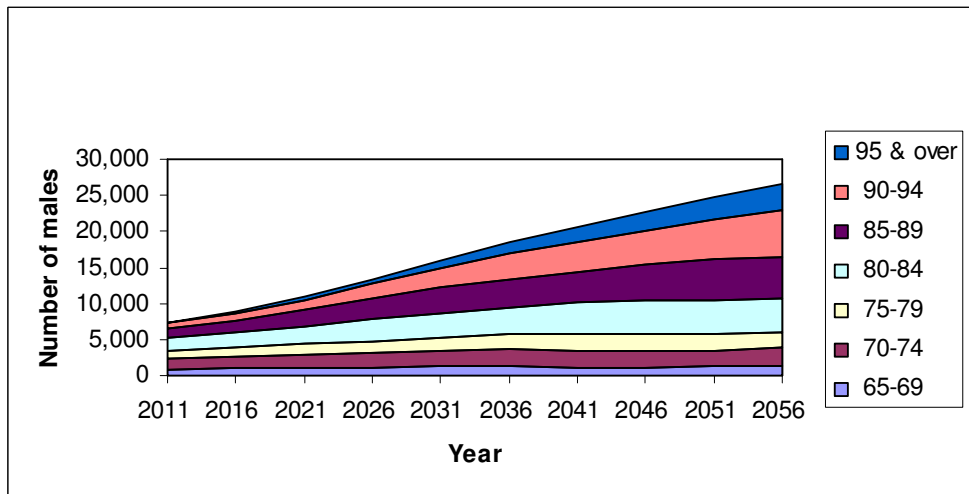
estimated that by 2056 there will be 38,000 women and 26,500 men affected by dementia.

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, however, the onset of dementia could be prevented or delayed, this could have very important implications for the numbers of people being diagnosed with dementia, for the services that would be required and for society as a

whole, as substantial additional costs accrue with an increased prevalence of the condition.

The Cost of Dementia Care

- 2.7 The costs of dementia care are substantial, both to the public purse and to those living with dementia and their families. The Alzheimer’s Society report¹² 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 was estimated at £31,300. These costs include informal care costs, 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.

Table 1: Estimated cost of dementia care in Northern Ireland

	£m	Uplifted to
	(2005/06 prices)	2009/10 prices
		£m

¹² Dementia UK; LSE, King’s College London and Alzheimer’s Society 2007

Informal care costs	149	165
Health and social care costs	93	103
Supported accommodation costs	163	180
TOTAL	405	448

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)	
Psycho geriatric 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 £230m at 2009/10 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 and supporting those with 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: Preventing or Delaying the Onset of Dementia

3.1 Dementia is not always preventable and certain risk factors are not modifiable. But some are, 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 time¹³.

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.

What are the Risk Factors for Dementia?

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

¹³ Jorm, AF, Korten, AE & Henderson, AS (1987) The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica*, 76, 465-479.

- 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 particularly Alzheimers' 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 prevention 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** - 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 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 Health¹⁴, Cardiovascular Services Framework, Mental Health Promotion Strategy, Quality and Outcomes Framework (QOF) in Primary Care and other strategies.

NICE Guidelines

3.9 Based on the limited evidence available the NICE/ SCIE guideline¹⁵ makes the following recommendations:

- *Screening for dementia*

¹⁴ Investing for Health: DHSSPS 2002

¹⁵ Dementia: supporting people with dementia and their carers in health and social care; Clinical guideline 42, NICE 2006

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

Way Forward in terms of Prevention

3.10 Since the evidence is not strong in relation to prevention, 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 under the care of their GP or secondary care team for conditions such as coronary heart disease, stroke, high blood pressure, diabetes, depression or learning disability. This provides an opportunity for GPs and secondary care professionals to promote healthy lifestyles and to pick up early signs of dementia and to attempt to minimise stigma.
- 3.12 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 as per existing guidelines as part of a primary prevention strategy.

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.

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.

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 regarding appropriateness of referral to genetic services for patients likely to have a genetic basis to their dementia and their unaffected relatives.

Summary

- 3.13 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. A number of action points are identified which link to other strategies and frameworks. These actions are designed to raise awareness on modifiable risk factors and the need to treat, if appropriate to do so.
- 3.14 The next sections will focus on those with a presumptive 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 treatment 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, commissioned 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 Society¹⁶. 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;

¹⁶Listening 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 it was 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 review¹⁷.

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.

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.

Values and Principles for Dementia Services

¹⁷ Consultation Report – Older People - Dementia and mental health issues; The Rural College 2005

- 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 he or she 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.

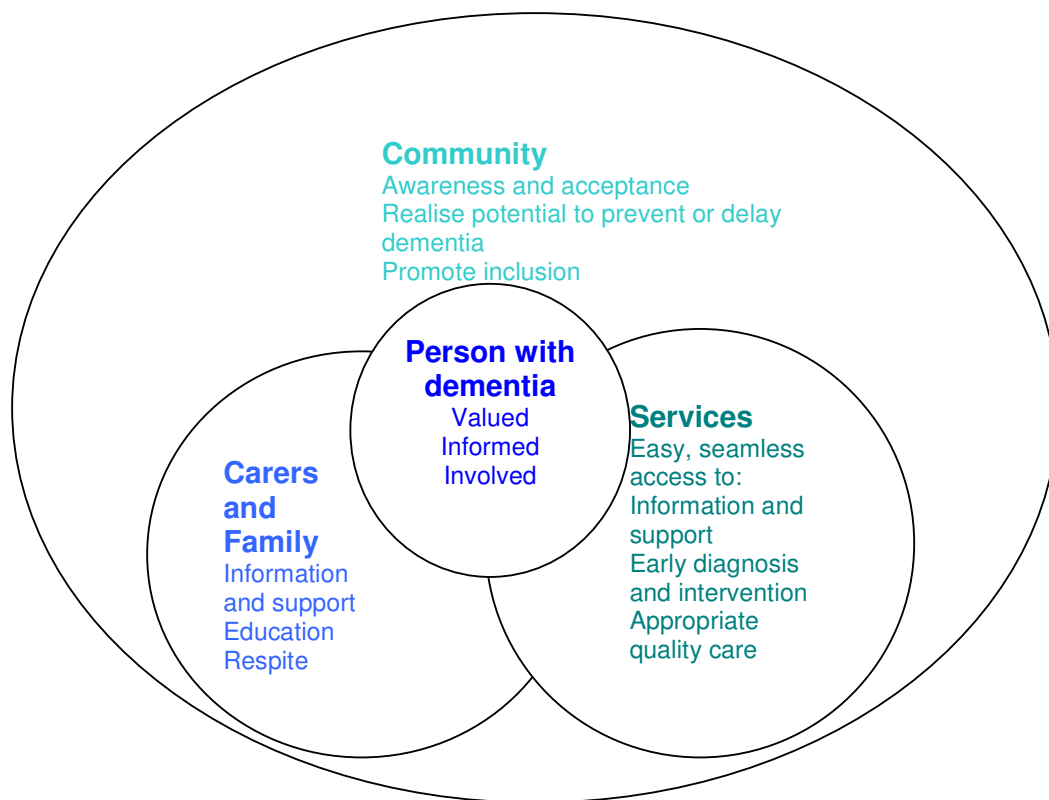
Section 5: A Model for Supporting People with Dementia and their Families

A Holistic Model for Supporting People with Dementia

5.1. What is needed is a holistic societal approach to supporting those living with dementia. 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 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, in as far as is possible. In assessing need and in planning and delivering care, it is essential to take time to listen to and understand the person and to communicate effectively with them and their carers.

Advocacy

5.3 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 heard.

5.4 People with dementia are at risk of being excluded from decisions being made about their care. For them independent advocacy is a 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.

5.5 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.

5.6 Advocacy not only supports individuals; it also supports, fosters and develops best practice in dementia care. Where appropriate, independent advocacy should be available to person's with dementia in order to support them in decision making, their families and carers and health and social care professionals who work with them.

Service Planning

- 5.7 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.
- 5.8 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. Self-directed support builds on the platform provided by Direct Payments legislation and offers an opportunity to meet the assessed needs of the whole person in a creative and flexible way. A person can buy self-directed support from a service provider, or by employing their own personal assistance. This support may be used as an alternative or an addition to services that are provided through the statutory sector. This approach enhances personalisation and choice and should become part of the mainstream of social care delivery for people with dementia and their families and carers.

Commissioning dementia services

- 5.9 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 would be invested to meet Ministerial priorities and improve health and social wellbeing and outcomes.
- 5.10 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.

5.11 The HSC Board and PHA will draw up standards to inform LCGs' commissioning for dementia care with a focus on service re-design. The standards will focus on:

- assessment of need, including carers' needs, and targeting of resources according to need; involving people with dementia and their families and carers, including promotion of advocacy and self directed support;
- promoting social inclusion of people with dementia through community based approaches;
- adopting a care management approach;
- recognising the important contribution made by the independent sector;
- developing appropriate linkages across the HSC and with appropriate agencies outside the HSC;
- developing standards for knowledge and skills of staff; and
- ensuring safety and quality of services

Service Delivery - A Staged Approach

5.12 Commissioning standards will inform the quality of service delivery for dementia care. Dementia has a fairly well defined pathway of progression, which calls for a staged approach to service delivery in relation to prevention, early recognition, treatment, care and support, appropriate to the needs of the individual and their family, as illustrated in Table 6 below.

5.10 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.

Table 3: DEMENTIA - A STAGED RESPONSE

Stage	Supporting Processes
Prevention Awareness of avoidable factors	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 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	Advice and information services, particularly in voluntary and community sector Support for individual and family to plan for the future Multi-disciplinary support within primary care 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

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)

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

- 5.14 This section highlights a holistic model for the integration of individuals living with dementia into our society. A fundamental part of this is the promotion of awareness of dementia, prevention, early recognition, assessment, treatment, 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.

The quality of dementia care is important. Therefore, there should be a regional approach to the development of standards to improve the commissioning and delivery of health and social care dementia services. 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.

The main action arising from this section is that:-

<p>Action</p>

<p>HSC Board and Public Health Agency will draw up standards to inform regional and LCG commissioning for dementia care as outlined above.</p>
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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 neighbouring jurisdictions.

Action

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

- address stigma;
- raise public awareness about what can be done to prevent 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 and secondary care, in statutory and non-statutory sectors, to improve knowledge of dementia 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 of the condition will reduce the stigma of dementia and will promote social inclusion for those who are living with dementia. Another reason for making people more aware of dementia is to 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 these people.

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 treatment which may slow the progression of the disease;
- receive care and support which may improve his or her quality of life; and
- make plans for the future, with his or her 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 people¹⁸, 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 here however identify 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 locality specific, for example, what services are available in their area. The Dementia Services Development Centre’s Northern Ireland Office has work in hand to develop an information pack for GPs in Northern Ireland; this

¹⁸ Mental Health Services for Older People; Performance Review Unit, DHSSPS 2005

should be available during 2010/11 and should be augmented with local information.

Who Should Provide The Initial Diagnosis?

- 7.3 Evidence suggests that GPs in Northern Ireland are making a diagnosis of dementia for at least 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.
- 7.4 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

The Dementia Services Development Centre – Northern Ireland will develop an information pack for GPs in Northern Ireland.

Trusts will supplement this with information on the local services available.

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

Access to Special Services for Assessment and Diagnosis

- 7.5 As stated above, the 1995 Northern Ireland Dementia Policy Review recommended that anyone suspected of having a form of dementia should be referred to a specialist diagnostic team. The Department of Health's National Dementia Strategy¹⁹ 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.
- 7.6 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

¹⁹ Living Well with Dementia: A National Dementia Strategy; Department of Health 2009

people being seen at these memory services would present with dementia, the services deal with other memory problems too.

- 7.7 Currently some memory services provide assessment and diagnostic services only, while others provide access to a range of care, support and advice before and after diagnosis. The latter model is the preferred model and 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 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

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

Actions

HSC Board in collaboration 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

- 7.9 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.

7.10 Once a person has been diagnosed with dementia, he or she needs 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

Information and Support at Time of Diagnosis

- 8.1 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

- 8.2 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.
- 8.3 One of the principles of a memory service shown in Table 7 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.

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

- 8.4 The immediate needs of someone who has recently received a diagnosis will vary considerably, depending on the stage of their dementia. For those in the early stages, initial requirements may be solely for information and advice, with a contact point should he or she wish to ask further questions later or to seek help as their condition deteriorates. Consistent advice is important; in order to assist the provision of information and advice in primary care, the Dementia Services Development Centre's Northern Ireland Office in 2010/11 is producing an information pack for GPs on the management of dementia.
- 8.5 Under the Quality and Outcomes Framework (QOF), GPs are encouraged to maintain a register of people in their practice who are diagnosed as having dementia. In 2008/09 almost 10,000 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. There is, however, no indication of the stage at which people are receiving a diagnosis and being placed on the registers.
- 8.6 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 his or her 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 2009 almost 80% of eligible patients in Northern Ireland practices had been reviewed in the previous 15 months.

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

Multi-disciplinary Approach to Meeting Need

- 8.8 A key objective of this strategy is to enable the person with dementia and his or her 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

- 8.9 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, therefore, 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.
- 8.10 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. Trusts are required to introduce the NISAT by June 2010 for the care of older people, including those with dementia.

Action

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

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

- 8.11 NICE guidance²⁰ recommends the use of the drugs donepezil, galantamine, rivastigmine and memantine as options only in the care of people who have moderate stage Alzheimer’s disease. The guidance specifies that only specialists in the care of people with dementia should initiate such treatment and that the patient should be reviewed every 6 months. This guidance has not been endorsed, however, for application in Northern Ireland.
- 8.12 In 2008 over 58,000 prescriptions were issued in Northern Ireland for these drugs with an ingredient cost of over £5m, the most common being donepezil, accounting for almost half of the prescriptions and half the total cost. These Alzheimer’s drugs account for around 1% of the total drugs bill.

²⁰ Technology appraisal guidance 111 - “ Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer’s disease (amended)” NICE (amended September 2007, August 2009)

8.13 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 treatment²¹. Set against this are the negative effects directly attributable to the use of antipsychotic medication, including additional cerebrovascular adverse events and additional deaths.

8.14 Work is being 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.

8.15 NICE guidance identifies a range of therapeutic interventions other than antipsychotic medication that should be available to people with 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. A range of therapeutic interventions, including psychological therapies, is available in Trusts here, but the overall pattern is patchy.

²¹The use of antipsychotic medication for people with dementia: Time for Action; Department of Health (2009)

Action

In developing the standards to inform commissioning for dementia care (see Section 5), 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.

Respite Care

8.16 Trusts provide a range of respite care through 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 respite to help cope with emergency situations, should they arise.

8.17 The Bamford review²² 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 2000 weeks of dementia respite care.

²² Living Fuller Lives; Bamford Review of Mental Health and Learning Disability (Northern Ireland) 2007

- 8.18 In developing additional respite provision it is important that innovative services are encouraged, maximising the potential of community-based options and the use of direct payments.

Action

In developing the standards to inform commissioning for dementia care (see Section 5), the HSC Board and PHA will ensure that a range of both traditional and innovative respite provision is developed to meet the needs of people with dementia and their carers.

Environmental Design

- 8.19 NICE – SCIE guidance²³ 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.

²³ The NICE-SCIE Guideline on Supporting People with dementia and their Carers in Health and Social Care; National Collaborating Centre for Mental Health 2007

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 an environmental assessment of existing facilities used by people with dementia and draw up a prioritised improvement plan for action as resources permit.

Assistive Technologies

- 8.20 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.
- 8.21 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.
- 8.22 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, the European Centre for Connected Health and Dementia Services Development Centre's Northern Ireland Office.

Supported Housing

- 8.23 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.
- 8.24 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.
- 8.25 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 Supporting People Fund.

8.26 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.

8.27 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. Work is under way on a comprehensive needs assessment for supported housing provision across all Trusts. From this strategic priorities are being identified and the capital and revenue costs, both Supporting People and health and social care costs, are being assessed. 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 standards 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, in collaboration with DSD and the NI Housing Executive, to include supported housing in their work on commissioning standards to inform Local Commissioning Groups.

Crisis Support

- 8.28 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

- 8.29 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.
- 8.30 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.

- 8.31 In view of the high levels of demand on acute hospital services by people with dementia and the 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.
- 8.32 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

- 8.33 Some people will still require admission to a mental health or geriatric unit for assessment, which will often include addressing medication and behavioural issues. Such admissions should however be short-term with a view to returning to the person's former home or securing a more suitable placement to meet his or her continuing needs.
- 8.34 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 included 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.

Palliative and End of Life Care

8.35 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 isn't currently possible. Services for patients with palliative 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.

8.36 DHSSPS has issued a strategy for Palliative and End of Life Care²⁴. The Strategy 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.

There are 25 recommendations which have been built into an Action Plan to enable the planning and delivery of quality palliative and end of life care over the next 5 years.

²⁴ Living Matters, Dying Matters – A Palliative and End of Life Care Strategy for Adults in Northern Ireland, DHSSPS 2010

- 8.37 In support of the strategy, a target was set, through the DHSSPS Priorities for Action, to ensure that by March 2011 each Trust has in place multi-disciplinary palliative and end of life care teams. 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.

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

- 8.38 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.
- 8.39 Diagnosis is especially difficult and often involves a lengthy process to eliminate other possible conditions. 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.
- 8.40 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

8.41 People with Down's Syndrome develop Alzheimer's at a much younger age than other people – some in their thirties - and virtually all people with Down's Syndrome who live long enough will develop this type of dementia²⁵. Many of these people will already have an established connection and history of support from learning disability services, and learning disability services should continue to lead in providing support for such individuals but should ensure that they also have access to dementia diagnostic and support services.

Action

Trusts will ensure that people with a learning disability and dementia are supported by learning disability services, with access to dementia services.

Summary

8.42 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

²⁵ Adults with Down's Syndrome and Alzheimer's Disease: McQuillan and Kalsy, The Learning Disability Review 2003

of timely information, enhanced respite and intermediate care, and appropriate home environments which support individuals to live as independently as possible. 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 dementia²⁶, 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 report²⁷ 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 financial 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

²⁶ 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.

²⁷ 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 therefore 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 In 2010/11, the Dementia Services Development Centre's Northern Ireland Office will develop 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 develop an acute care pack for dementia 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

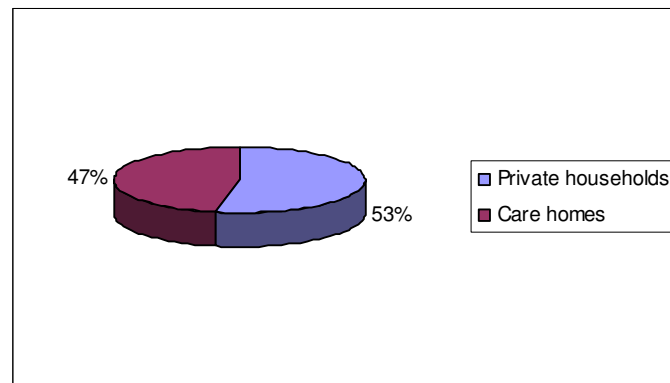
9.7 This section highlights the importance of understanding the care needs of individuals with dementia when they are admitted to an acute hospital ward. In order to enhance the quality of care and improve outcomes, all such individuals should have a specific care plan in place. An “acute care pack”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

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 homes²⁸, 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 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,

²⁸ Dementia UK – Northern Ireland Supplement; LSE, King’s College London and Alzheimer’s Society 2007

with awareness of 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.

- 10.4 As in other settings, environmental design can have a significant impact on the quality of life for people in care homes. Prescribing is the most common medical intervention experienced by elderly residents in nursing and residential care homes.
- 10.5 A Northern Ireland study²⁹ 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.
- 10.6 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.
- 10.7 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;

²⁹ Patterson S M, Hughes C M, Crealey G, Caerwell 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

- 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;
- physical health needs assessment to include, for example, pain and depression, using recognised assessment tools;
- dining experience, reviewing nutrition, mealtimes, hydration and dignity at 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 commissioning framework for dementia services.

Summary

- 10.8 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.
- 10.9 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. The carers' strategy³⁰ is an inter-agency strategy, dealing with health and personal social services, employment, training, education, availability of information and support services. Initiatives such as carer assessments and the introduction of Direct Payments give carers the opportunity to discuss and to plan for what they need by way of emotional, practical and financial support.
- 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

³⁰ *Caring for Carers: Recognising, Valuing and Supporting the Carer's Role: DHSSPS 2006*

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 As part of the implementation of the wider NISAT programme, Trusts will be required to use this carer's tool for all assessments in the older people's programme by June 2010 and the use of the carer's tool in other programmes is also being encouraged. 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 2009³¹.

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;

³¹ 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 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.

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, is currently developing a guide for carers informing them about the process of discharging a patient from hospital and intermediate care, the decisions that may have to be made and what they can expect to happen during the discharge process. A guide is also being developed for managers and policy makers to help HSC Trusts develop policy and practice in identifying and involving carers in planning for a patient's discharge from hospital and intermediate care.

Actions

DHSSPS will issue a Guide for Carers, to inform them about the process of discharging a patient from hospital and intermediate care services.

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 will be 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.

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. 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.
- 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 his or her 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 in the best interests of the individual.
- 12.3 The proposed single Bill will be a very large and complex piece of legislation which has not been attempted in any other jurisdiction. It will not be possible to enact this within the current Assembly period.

Impact of the proposed Legislation on those with Dementia

- 12.4 Those with dementia may fall within the remit of the single Bill, depending on the extent of their condition. The new legislation will apply where an individual 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, care and welfare decisions such as where a person will live and medical treatment decisions.

12.5 The legislation will provide for a number of substitute decision making arrangements such as advance decisions, lasting powers of attorney, court appointed deputies, a hierarchical tier of approved interventions and a general authority to allow doctors and others to act. In all cases of substitute decision making those making the decisions will be required to act in the best interests of the individual affected. Advance decisions and lasting powers of attorney are 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.

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

12.6 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 had been produced to promote base practice in this area and was published by the DHSSPS in January 2010.

12.7 In addition to above, the single Bill will provide a right of independent advocacy to those affected by the legislation. 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.

Action

Subject to Executive approval, the DHSSPS will develop new mental capacity and mental health legislation for introduction in to the Assembly in 2011/12.

Summary

12.8 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 and ensuring that potential treatments are trialled and made available to patients as quickly as possible.
- 13.2 Funding for 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 treatments 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 and, 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 is planning a 2010 launch of its Institute of Health and Wellbeing. Education and research on mental health, including dementia, will be the Institute's major initial focus. The Institute 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 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.

Actions

HSC R&D will continue to support NICRN (Dementia). Its roll-out across NI HSC Trusts will be evident during 2010.

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

13.11 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 the commissioning of health and social care services and in the promotion of 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 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 Minister for Health, Social Services and Public Safety on progress against the actions on a 6-monthly basis.
- 14.4 It is proposed that, subject to evaluation of the current three year pilot in Northern Ireland, service improvement and promotion of best practice will also be supported by the Dementia Services Development Centre, which will function as a hub for provision of dementia-specific training, education, consultancy, information and research services. The centre will help to drive change and enhance services across the spectrum of care in the statutory and non-statutory health, social care and housing sectors.

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, 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.

14.7 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.

It is not possible at this stage to cost accurately each of these elements and in practice some of the proposed service developments would have to be taken forward on an incremental basis, but it is estimated

that by year 3 of the strategy, an additional annual revenue investment of £6-8m would be required along with known capital costs of supported living schemes.

- 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 would 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. The National Audit Office estimated that failing to recognise the needs of people with dementia in acute hospitals led to excess costs of more than £6m per year in an average general hospital with 500 beds³². Applying this to Northern Ireland acute bed provision would release an estimated £40m.

³² Improving services and support to people with dementia; National Audit Office (2007)

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

Preventing 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 developing initiatives that may reduce serious head injuries	Public Health Agency	By March 2011	1,2
3. Primary care professionals will opportunistically offer lifestyle advice and if appropriate review and treat vascular and other modifiable risk factors as per existing guidelines as part of primary prevention.	HSC Board and Public Health Agency in collaboration with LCGs	Ongoing	1,2
4. 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. 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. Consideration will be given to the addition of primary prevention targets for dementia 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. Consideration will be given to the further development of secondary prevention targets to the Dementia Indicator within QOF.	HSC Board and Public Health Agency	Ongoing	1,2

Action Plan

Preventing or Delaying Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
7. Clear protocols will be developed 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 September 2011	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 prevent 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 December 2011	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 and secondary care, in statutory and non-statutory sectors, to improve knowledge of dementia 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	By March 2012	3,4,5,6
11. Develop an information pack on dementia for GPs in Northern Ireland	Dementia Services Development Centre NI	By March 2011	4,5,6
12. Supplement this information pack with information on local services available	HSC Trusts	By March 2011	4,5,6

Action Plan

Promoting Early Assessment and Diagnosis

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
13. 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 and LCGs	By March 2011	3,4
14. Ensure that memory services that meet the principles outlined in Table 4 above and ensure that the agreed minimum services are available to people in their area.	HSC Trusts	By March 2012	3,4
15. 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 2012	3,4
16. Draw up criteria for referral from GP practices to the memory service	HSC Board in collaboration with the Public Health Agency and LCGs	By March 2012	3,4,6
17. 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 2012	3,4,5,6
18. Conduct a review of the effectiveness of memory services	Regulation and Quality Improvement Authority	By September 2013	3,4

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
19. 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 June 2010	2,4
20. Develop standards to inform commissioning for dementia care to include: <ul style="list-style-type: none"> • information provision to individuals, families and carers; • standards for quality of care, therapeutic interventions and medicines management in the statutory and non-statutory sectors; • standards for a range of both traditional and innovative respite provision to meet the needs of people with dementia and their carers; • environmental standards for all new facilities; • standards on supported housing; • standards for memory services provision to enhance early diagnosis and an integrated pathway approach; • standards for tertiary service provision. 	HSC Board in collaboration with the Public Health Agency and other relevant organisations	By June 2011	3,4,5
21. 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 March 2013	3,4,5

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
22. Carry out an 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	By December 2012	3,4
23. 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
24. 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	By March 2013	2,4,5
25. 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
26. 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 December 2011	4,5
27. Review current 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 June 2011	4,5

Action Plan

Supporting People with Dementia

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
28. 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
29. Develop a regional care pathway for younger people with dementia, including access to the regional tertiary memory service (action 15 above)	HSC Trusts	By September 2011	3,4,5
30. Ensure that people with a learning disability and dementia are supported by learning disability services, with appropriate access to dementia services	HSC Trusts	By March 2011	3,4,5
31. 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 2011	3,4,5
32. Develop an acute care pack for dementia to enhance knowledge and skills on the care of individuals with dementia, when admitted to acute wards	Dementia Services Development Centre (Northern Ireland)	By March 2011	4,5,6
33. Develop standards for commissioning dementia care in care homes (see action 20)	HSC Board, in collaboration with the PHA and Trusts	By September 2011	3,4,5

Action Plan

Supporting Carers

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
34. Implement the NISAT carer's assessment tool in respect of those caring for people with dementia	HSC Trusts	Ongoing	5
35. 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	HSC Trusts	In line with timescales for work arising from joint review	5
36. Issue guide for carers informing them about the process of discharging a patient from hospital and intermediate care	DHSSPS in collaboration with the Carers Implementation Group	By September 2010	5
37. 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 2010	5

Action Plan

Legislation

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
38. Develop and ensure introduction of new mental capacity and mental health legislation	DHSSPS	Enactment during 2012/13 Assembly session	1,2,3

Action Plan

Research

Action	Lead Responsibility	Target Date	Underpinning Values and Principles
39. Continue to support NICRN (Dementia) with its roll-out across NI HSC Trusts evident during 2010	Public Health Agency in collaboration with universities and non-statutory sector	During 2010 and beyond	1,4
40. 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 by early 2011	1,4
41. 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
42. 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 by April 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 demand on the health and social care system, in the context of the Executive's Programme for Government, and in ways which are consistent with 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.

Appendix 5

MEMBERSHIP OF STEERING GROUP

Maura Briscoe (Chair)	Director of Mental Health and Disability, DHSSPS
Brian Barry	Acting Director of Older People Services, Primary Care & Integration, Belfast HSC Trust
Carol Cousins	Regional Manager, Four Seasons Healthcare
Heather Cousins	Housing Division, DSD
Clifford Coulter	Senior Commissioning Accountant, HSC Board
Oscar Donnelly	Director of Mental Health and Disability Services, Northern HSC Trust
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
Kevin Keenan	Assistant Director of Social Services, HSC Board
Mike Mannion	Psychiatrist of Old Age, Northern HSC Trust
Brian O'Hagan	Carer
Peter Passmore	Professor of Ageing and Geriatric Medicine, Queen's University, Belfast

MEMBERSHIP OF PROJECT TEAM

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Tom Esmonde	Consultant Neurologist, Northern HSC Trust
John Farrell	General Medical Services, DHSSPS
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Marie Heaney	Service Manager, Older People's Services, Belfast HSC Trust
Phil Hughes	Head of Mental Health and Older People Services and Professional Lead for Social Work , Northern HSC Trust
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Deborah Magee	Financial Policy and Accountability, DHSSPS
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