

## **Scotland's National Dementia Strategy: 2013-16**

### **Ministerial Foreword**

This is Scotland's second National Dementia Strategy. The first was published in 2010 and focused on improving the quality of dementia services through more timely diagnosis and on better care and treatment, particularly in hospital settings. It began the process of the transformation of care across all sectors in anticipation of the growing number of people with dementia.

Although we do not underestimate the scale of the challenge over the next three years, and beyond, we have notable achievements to build on. We've increased diagnosis rates, with around 64% of people with dementia in Scotland now receiving a diagnosis. That's significantly better than rates in other parts of the UK, but we must sustain and extend that performance.

Although a diagnosis of dementia has a huge impact on individuals and families, timely and sensitive diagnosis, backed by effective and holistic post-diagnostic support, is vital in helping people build their personal resilience and knowledge about dementia and enabling them to live a good quality of life at home for as long as possible. That's why we introduced a national commitment on post-diagnostic support for everyone diagnosed from 1 April this year. There are, of course, many people who have been living with dementia in our communities and who need good quality services as their symptoms advance and they begin to need more intensive support. We'll also take more action to change and improve services for those people.

There are also huge challenges for us in ensuring that people with dementia are not admitted to hospital unnecessarily and that they get effective and dignified care while in hospital. We have recently launched a National Action Plan to support NHS Boards in helping to make those changes and to maximise workforce initiatives such as the Alzheimer Scotland Dementia Nurse Consultants and the Dementia Champions.

We'll also work closely with The Life Changes Trust as they begin to make funding available from this year for initiatives across Scotland to build dementia-aware local communities – among other benefits, these will help tackle the isolation and depression often felt by people with dementia and help them remain connected to their friends and neighbours.

All of this activity is aligned with our 2020 vision for health and care in Scotland, which will work to enable all people, including those with dementia, to live well for longer at home or in a homely setting. This will be backed by an integrated health and care system with a focus on areas like supported self-management and on ensuring community-based health treatment wherever and whenever possible.

The last three years have been notable for a very strong partnership approach in implementing and developing dementia policy. I greatly value the significant role and expertise of Alzheimer Scotland and others in this process. People with dementia and their carers are continuing to take a full role in helping to improve services, both

nationally and locally, and their participation and the wealth of experience they bring is hugely important. I would also like to give recognition to all of you who contributed to this strategy as part of the Dementia Dialogue process. I look forward to our continuing collaborative approach to further improve dementia services, and people's experience of them, over the next 3 years.

## **Introduction**

Dementia is one of the foremost public health challenges worldwide. As a consequence of improved healthcare and better standards of living more people are living for longer. This means in Scotland that the number of people with dementia is expected to double between 2011 and 2031. This presents a number of challenges, most directly for the people who develop dementia and their families and carers, but also for the statutory and voluntary sector services who provide care and support. Over time we expect that a greater proportion of health and social care expenditure will focus on dementia, and there is evidence of that change already. There are no easy solutions and transformation will take time. This document sets out what we will do in the next three years.

There is no particular measure which can prevent dementia. The interplay between the benefits of a healthy lifestyle and the increasing risk of developing dementia with age is complex and difficult to assess. There is evidence that healthy living behaviours, such as better diet or physical activity, may reduce the risk of a person developing dementia or delay its onset. At the same time, the increase in life expectancy, also a consequence of healthy living behaviours, is the main factor behind the increasing number of people in Scotland with dementia. More work is needed to understand these interactions at a population level, though the benefits to the individual of healthy living are clear.

## **Preparation of this Strategy**

This Strategy has been produced on the basis of participation and dialogue. Last October we produced a paper setting out our assessment of progress to date in taking forward Scotland's Dementia Strategy and of the continuing challenges. Following that we took forward our National Dementia Dialogue in conjunction with Alzheimer Scotland. This included a series of events which also allowed discussion of Alzheimer Scotland's new policy paper on integrated community-based support for dementia, based on their "8 Pillars" model and the Big Lottery's Life Changes Trust. At the conclusion of that process in February we published an initial Proposition Paper. This paper reported a strong consensus on the actions that should form the basis of our second dementia strategy. That paper was also the starting point for the work undertaken by an expert group which met between March and May to support the production of this document.

## **Challenges**

Over the next period of time there are three main challenges that we must address.

**First**, we must offer care and support to people with dementia and their families and carers in a way which promotes wellbeing and quality of life,

protects their rights and respects their humanity. This is a moral imperative and it is unacceptable that too often the experience of people does not meet this standard.

**Second**, we must continue to improve services and support from when someone presents for diagnosis, and throughout the course of the illness, including the support needs of carers. This support must be truly person centred, and should understand care and support from their perspective, not the perspective of service managers or clinicians.

**Third**, we must recognise that with increased life expectancy the challenge of providing high quality care and support to people with dementia and their carers will increase over time. We must embrace the process of redesign and transformation of services to ensure that we deliver services effectively and efficiently.

We have worked on each of these challenges since 2007 with success, but there is still more to do.

## **Progress and Achievements**

This government made dementia a national priority in 2007, set a national target on improving diagnosis rates in 2008 and published an initial 3-year National Dementia Strategy in 2010, underpinned by a rights-based approach to care, treatment and support. Our work over the last three years has been based on strong collaboration in developing and implementing the strategy in a coordinated way

In 2011 we published the Standards of Care for Dementia in Scotland as well as the *Promoting Excellence* framework, which supports the health and social services workforce to meet the standards.

Our 3-year diagnosis target was achieved nationally and the Alzheimer Society's second annual dementia map – published in January 2013 – shows that at March 2012, in Scotland around 64% of those with dementia were being diagnosed. This is significantly higher than England and Wales and shows what can be achieved by clinicians and statutory and voluntary organisations working together.

From April 2013, we have introduced a further target which guarantees that everyone newly diagnosed with dementia will be entitled to at least a year's worth of post-diagnostic support, coordinated by a named Link Worker.

Since 2011 the Chief Nursing Officer has led an improvement programme with NHS Boards on the care of older people in hospitals. Alzheimer Scotland Dementia Nurse Consultants have been appointed to Boards across Scotland and 300 Dementia Champions were in place by March 2013.

We have provided integrated improvement support across local health and care systems, in order to help facilitate local whole-system change in dementia services and to provide evidence on the value and effectiveness of targeted improvement support and challenge. The report *Emerging Messages From The Dementia*

*Demonstrator Sites*, shows the impact of the strategy and of the demonstrator work in helping local partnerships work together to develop whole-system approaches to dementia, including through redesign and disinvestment in institutional services to invest in the community.

## **Policy Context**

Our work on dementia is one strand of the wider work that we are taking forward to transform and improve health and social care services. Other key strands of that work include:

**Integration of Health and Social Care:** the Scottish Government is taking forward legislation to allow for the local integration of adult and older people's health and social care services in Scotland; the need to improve the response to dementia is one of the key policy drivers for this work and health boards, local authorities and the voluntary sector are involved in this process.

**Reshaping Care for Older People/Change Fund:** the Scottish Government is investing £300 million to facilitate changes in the way services are designed and care is delivered, including services for people with dementia. Health and Social Care Partnerships will set out their intentions for the future delivery of care for people with dementia and their carers in their respective planning documents and have the ability to develop plans together through joint commissioning processes.

**Carers Strategies:** *Caring Together: The Carers Strategy for Scotland 2010-15*, which is underpinned by £98 million of investment between 2008 and 2015, recognises that carers must be seen as equal partners in the delivery of care as their support enables people with dementia to live at home and in their own communities safely, independently and with dignity.

**Self-directed Support:** self-directed support is a major reform to the way in which social care and some healthcare services are delivered and gives greater choice and control to those who receive support; the Alzheimer Scotland pilot on self-directed support in Ayrshire showed that self-directed support offers benefits to people with dementia.

**Housing:** older people, including those with dementia, consistently tell us that they want to live in their own homes for as long as possible, rather than in hospitals and care homes. *Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012 – 2021* emphasises the role of housing and housing-related support in 'shifting the balance of care' towards independent living in the community and reducing the use of institutional care settings.

**Palliative Care:** *Living and Dying Well; a National Action Plan for Palliative and End of Life Care* (2008) and *Living and Dying Well: Building on Progress. Work* (2011) promote the provision of palliative and end of life care to all, regardless of diagnosis, and is consistent with, and highly supportive of, improvements in care for people with dementia and their families.

## **Key Outcomes**

The key outcomes for this Strategy, which emerged from the National Dementia Dialogue as priorities were:

- more people with dementia living a good quality life at home for longer.
- dementia-enabled and dementia-friendly local communities, that contribute to greater awareness of dementia and reduce stigma.
- timely, accurate diagnosis of dementia.
- better post-diagnostic support for people with dementia and their families.
- more people with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness.
- better respect and promotion of rights in all settings, together with improved compliance with the legal requirements in respect of treatment.
- people with dementia in hospitals or other institutional settings always being treated with dignity and respect.

## **Commitments**

### **Supporting Timely and Accurate Diagnosis**

People can be reluctant to go to the doctor when they are worried that they may have dementia because the benefits of diagnosis for them are not clear. There are challenges around diagnosis and we recognise that accurate diagnosis in the earlier stage of the illness can be difficult. But we also know that appropriate support in the early stages can have a very significant impact on the degree to which someone is able to manage the condition over time and live independently.

Effective diagnosis – including how it is imparted and how people are supported immediately after diagnosis – can mean that the traumatic aspects of receiving a diagnosis can be counterbalanced. Timely diagnosis enables people to plan ahead while they still have capacity to do so and means they can get early and effective access to drug and other interventions which can sustain their cognition, mental wellbeing and quality of life. Current medications available for some forms of dementia can help to slow the symptoms and sometimes improve symptoms in the short term, although they do not treat the underlying disease; the main form of treatment is human intervention. Too often in the past diagnosis has been late, well after the condition is having a significant impact on daily life, causing confusion and distress to the individual and family around future planning

The Scottish Government's early strategic focus from 2007 was therefore on increasing diagnosis rates as the gateway to services. The national diagnosis HEAT target (2008-2011) was achieved nationally and has been the building block for the

new post-diagnostic target. The target for diagnosis is set at around 50% of presumed prevalence, recognising that the value of diagnosis is linked to timely access to appropriate information, support and services.

### Comparative diagnosis across the UK

The Alzheimer Society's annual dementia map– the second of which was published on 15 January 2013 - shows comparative performance on dementia diagnosis across the UK and details performance within each part of the UK as well.

The map uses the *Dementia UK* Prevalence Model. As indicated earlier, this model shows that, up to March 2012, in Scotland around 64% of those with dementia were being diagnose. This contrasted with around 44% in England, 38% in Wales and 63% in Northern Ireland; in 2008 the figure for Scotland was similar to that for England. These figures do not tell us at what stage in the illness the diagnosis is being made.

We helped achieve the national diagnosis target by providing national improvement support, focusing on areas such as improving staff awareness of the value of early diagnosis and better information sharing between primary and secondary care. We will continue to focus on sustaining and further improving diagnosis rates, with a next phase of improvement support identifying and targeting areas where extra support and challenge is needed.

**COMMITMENT 1: We will sustain and, where appropriate improve further, dementia diagnosis rates.**

### **Providing post-diagnostic support**

Supporting people with dementia and their families and carers (commonly known as post-diagnostic support) was one of the key change areas in the first Dementia Strategy. Better post-diagnostic support helps people to adjust to the diagnosis and its likely impact – both practical and emotional – and help them plan for future care, including through advanced care planning for the delivery of preferred end of life care. It can help services work better with people's "natural" family supports during this important stage of the illness. It can contribute to people with dementia living a better quality of life and living as independently as possible and as part of their community as for as long as possible.

Our new national target for dementia sets out the commitment:-

**'To deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a Link Worker, including the building of a person-centred support plan'**

The post-diagnostic target is designed to give people time and space to access services and receive high quality support in a way that meets their individual needs over the course of a year. It recognises that a diagnosis of dementia can have a huge impact on individuals, carers and families and that coming to terms with a diagnosis and what it will mean for an individual and their loved ones can take time and expert support. This is a 3-year target, with services expected to be delivering the commitment to everyone newly diagnosed by March 2016 (though Boards are collecting data from April 2013).

While the target is primarily designed to support people in the earlier stages of the illness, it applies equally to everyone diagnosed from 1 April 2013 and in every care setting, including care homes and hospitals. We will do more work this year to ensure that implementation of the target is appropriate and meaningful for people in those settings who are diagnosed later in the journey of the illness. We will also undertake an Equality Impact Assessment to ensure that any barriers to accessing post-diagnostic support – including by age, disability, ethnicity, sexual orientation or gender – are identified and addressed

### Five Pillars of Support

The post-diagnostic HEAT target is informed by Alzheimer Scotland's "5 Pillars" model of post-diagnostic support

The 5 Pillars highlight key areas of activity for post-diagnostic support. It will be essential that each person's needs are assessed against each of the 5 pillars. The Link Worker will operate at a minimum of 'Enhanced' level on the *Promoting Excellence* framework and will have had specific training in post-diagnostic support and in the 5 Pillars model before undertaking this role.

The Link Worker will work flexibly with each person with dementia, and with the person's family and natural support networks, introducing each of the 5 pillars in a personalised and holistic way and at the appropriate time for the person. National training will be available to help services to understand and deliver the commitment. Recognising the key roles of carers and families is essential in helping design and implement a person-centred support plan.

Although everyone diagnosed from 1 April 2013 will be allocated a Link Worker, some individuals may not want support right away, or may decide they do not want support further down the line before the end of the 12 months. There may be some people who do not want any support at all during the 12 month period. The Link Worker will keep in regular contact with every individual on their caseload (as appropriate) and the post-diagnostic support will be available for the individual to access in a manner of their choosing and which suits their individual needs and circumstances.

At the end of the 12 month period, each individual's support needs will be assessed. We expect people in the earlier stages of the illness will be assessed as being able to move to self-management, drawing on support when needed; other people may need more time-limited support while others with complex needs may require longer term support and treatment.

## Testing the HEAT Target

During the last twelve months, the Scottish Government has undertaken a significant amount of work with others in testing the workforce and resource implications of implementing the HEAT target. We supported 4 test sites – in South Ayrshire, Glasgow City, Argyll and Bute and East Renfrewshire – to develop resources which enable services across all sectors to map current service provision, cost the delivery of the target and begin to redesign the mix of local services.

We have also worked with NHS National Services Scotland to develop a measurement framework and data sets which will track progress against the target, including a minimum national data set.

People with a new diagnosis of dementia will also have opportunities to be partners in dementia research, led by the Scottish Dementia Clinical Research Network, should they wish to do so.

**COMMITMENT 2: We will transform the availability, consistency and quality of post-diagnostic support by delivering the new post-diagnostic HEAT target.**

## **Strengthening Integrated Support**

People with dementia can benefit from timely health and social care supports, to enable them to live a good quality life at home for as long as possible as the illness progresses. Historically, interventions have tended to occur at a stage when the person with dementia's physical and mental capability and resilience have deteriorated. In line with key principles underlying the integration of health and social care, we need to move more towards a system of care which maximises and promotes resilience and independence and which supports and promotes the capabilities of the person with dementia at home during the moderate to severe stages of the illness, as they move from self-managing the illness with support to needing more intensive support.

The Standards of Care for Dementia recognise the importance of people with dementia being enabled not only to stay at home and in their community. They should also be, as much as possible, visible, connected and active participants in their local communities – including in social events, the arts, and religious and community groups. Nurturing and supporting dementia-aware and dementia-friendly local communities is important in creating and sustaining a society where people with dementia and their families and carers feel included and at the heart of the community. Beginning this year, the Life Changes Trust (LCT) will manage a ten-year, £50 million investment by the BIG Lottery Fund focusing on two specific groups – young people who are in the process of leaving care, and people with dementia and their carers. The investment is likely to focus on areas such as developing dementia friendly and dementia enabled communities, peer support and befriending. The LCT will set out its strategy and plans for the next 3 years shortly.

While the post-diagnostic commitment for everyone diagnosed on or after 1 April 2013 will also help drive wider changes in dementia services, we know that there are a large number of people who have been living with dementia who are at the stage of the illness when they require more intensive support.

### 8 Pillars Model of Community Support

Alzheimer Scotland's policy paper *Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support* proposes an integrated care model to address these issues. As part of the Dementia Dialogue we provided an opportunity for stakeholders to hear more about this model and give their initial views. Feedback was generally positive about the aims of the model.

This 8 Pillar model focuses specifically on that stage of the illness where more intensive community services are needed to enable people to stay living well and as independently as possible at home for as long as possible. The model is based on a coordinated, holistic approach which also aims to provide continuity of care in the form of that key contact point for people with dementia and their carers.

The 8 Pillars are:-

- Pillar 1: The Dementia Practice Coordinator (to coordinate the 8 Pillars)
- Pillar 2: Therapeutic interventions to tackle the symptoms of the illness
- Pillar 3: General health care and treatment
- Pillar 4: Mental health care and treatment
- Pillar 5: Personalised support
- Pillar 6: Support for carers
- Pillar 7: Environment
- Pillar 8: Community connections

We need to gather more evidence about the effectiveness of this model of care and support. In partnership with COSLA, Alzheimer Scotland and others we will test the 8 Pillars model across a range of environments (for example, urban, rural and island) and with different hosting arrangements (for example, primary care, local government and integrated services). This will allow us to test and develop the approach and follows the approach we took to testing the post-diagnostic HEAT target.

**COMMITMENT 3: We will test and evaluate a range of approaches to providing better integrated care and support on the basis of the 8 Pillars model, centred on a Dementia Practice Coordinator role.**

### Allied Health Professional (AHP) Led Interventions

We previously commissioned a review of the literature on Allied Health Professionals-led interventions for people with dementia. What we found was a growing evidence base supporting active non-pharmacological interventions by

AHPs. The evidence provided important insights for developing and testing future interventions for people with dementia, carers and families.

To build on this work, we will work with Alzheimer Scotland and AHPs to produce an evidence-based policy document that will outline the contribution of the AHPs to the 8-Pillar model (and the contribution of the AHPs to the key messages in the Dementia Strategy). The outcome of this work will help ensure that people with dementia, carers and families are provided with AHP information appropriate to their needs and that AHPs are in a position to provide advice, education and information to people with dementia, their families and carers when they need it.

**COMMITMENT 4: We will commission Alzheimer Scotland to produce an evidence based policy document outlining the contributions of AHPs to ensuring implementation of the 8-Pillar model.**

### Housing Support and Interventions

As people age, their housing needs change and some people, such as those with dementia and mobility problems, will also need specialised housing-related support services. If these needs are not met, it may be more difficult for people to remain in their own homes.

A familiar home environment is particularly important to people with dementia. Most people with dementia live in their own homes in the community but in homes that were not built to today's standards of accessibility. Well-designed housing is particularly important to people with dementia and can extend the amount of time that they are able to remain living at home, by reducing accidents and delaying the need for residential care.

Since most people with dementia live in ordinary housing, the housing services that support them to remain in this environment are key, with housing adaptations, handypersons, small repairs and housing support services of particular importance. These services are generally provided by social landlords (local authorities and housing associations) for their tenants, and by Care and Repair services for people living in private sector housing.

The frontline housing officers and technical staff, who deliver these housing-related services, may often be working with people who have dementia, most likely in the early (sometimes undiagnosed) stages. Many staff would benefit from an increased understanding of what dementia is, how to identify the signs and what to do next to help support people with dementia.

With the importance of housing design and staff awareness in mind, the Scottish Government and Joint Improvement Team commissioned the Chartered Institute of Housing Scotland and the Dementia Services Development Centre to undertake a project to improve housing and housing services for people with dementia. Key elements of the project are:

- awareness raising: a national survey, followed by practitioner meetings, which enabled assessment to be made of the knowledge and awareness of dementia among housing staff. A series of seminars and events during summer 2013, along with new training resources, will help to increase knowledge of dementia support and design among housing staff and their organisations.
- design practice guidelines: a new guide, *Improving the Design of Housing to assist People with Dementia*, pulls together substantial guidance of housing providers on design features, including the prioritisation of those which are most important to support cost-effective adaptation of housing for people with dementia. It will be available online without charge.

**COMMITMENT 5: We will take further action to support safe and supportive home environments and the importance of the use of adaptations and assistive technology, in maintaining the independence and quality of life of people with dementia and their carers.**

## Rights-based care

In the first Dementia Strategy, we made a commitment to the production of Standards of Care for Dementia in Scotland, based on the Charter of Rights developed by the Parliamentary Cross Party Group on Alzheimer's disease. The dementia standards are based on six overarching statements of individual rights:

- I have the right to a diagnosis
- I have the right to be regarded as a unique individual and to be treated with dignity and respect
- I have the right to access a range of treatment and supports
- I have the right to be as independent as possible and be included in my community
- I have the right to have carers who are well supported and educated about dementia
- I have the right to end of life care that respects my wishes.

The standards are designed to inform care providers of their responsibilities and to help them self-audit services and to empower people with dementia and their carers. A guide to the standards is available from Alzheimer Scotland. In conjunction with *Promoting Excellence*, they form a crucial part of work to improve knowledge and practice. Rights-based training has been developed for care home staff. Reports by regulatory organisations have commented favourably on improved attitudes, especially in general hospitals. However, while there have been many improvements, some reports have found:

- environments, especially in hospital, that are not sufficiently enabling for people with dementia a lack of individual care planning based on the

individual's life story variable practice in assessing capacity to consent to treatment and giving treatment lawfully. (The recent report by the MWC suggests this is better than it was four years ago but needs to improve further)

- some lack of compliance with best practice when making decisions not to resuscitate.

We will take more action specifically in relation to dignity and respect, including attention to human rights and the principles and requirements of mental health and incapacity legislation, including:-

- earlier identification of people with palliative care needs, to promote advance care planning, to facilitate the sharing of key information across settings through the development and roll out of the Electronic Palliative Care Summary
- promoting best practice in advance care planning based on the wishes of the individual and taking account of carers' views in accordance with the principles of incapacity legislation
- promoting best practice in assessing capacity and providing care and treatment in line with the law
- in particular, promoting best practice on Do Not Attempt Cardiopulmonary Resuscitation decision-making and communication and supporting, with greater awareness of proper procedures for making decisions for people with dementia who lack capacity.

**COMMITMENT 6: We will take further action to support and promote best practice in advance care planning, the assessment of capacity to consent to treatment and adherence to proper procedures for making decisions for people with dementia who lack capacity**

**COMMITMENT 7: We will publish a report on implementation of the dementia standards to date.**

### **Workforce skills and competencies**

In the first Strategy, the Scottish Government made a major commitment to take a strategic approach to improve staff skills and knowledge on dementia in both health and social care settings. The work will continue through to 2016, building on progress so far in increasing capability in the workforce, and embedding and sustaining change.

*Promoting Excellence: a framework for all staff working with people with dementia, their families and carers* was launched in June 2011, together with the Standards of Care for Dementia in Scotland. Between 2011 and 13 NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) have undertaken a programme of work to support workforce development against the *Promoting Excellence* Framework, including the development of a number of educational resources, the roll out of a number training programmes, and establishing infrastructures to ensure spread and sustainability of this work. A *Promoting Excellence* Programme Board, Chaired by The Chief Executive of Alzheimer Scotland, has guided implementation of this work

**COMMITMENT 8: We will continue to improve staff skills and knowledge by working with NHS, NES and SSSC to take forward a second *Promoting Excellence* training plan across the period of this Strategy.**

### Digital Platform

One of the themes that emerged from the National Dementia Dialogue was a desire for greater access to skills and knowledge by carers to improve their ability to provide effective support. Technology is one mechanism that we can use to respond to this request for help. There is already a range of electronic information and training resources prepared by Scottish public and voluntary sector organisations aimed at people with dementia, their carers and families, and those who work with them. From a user's perspective, however, these resources can be confusing and difficult to navigate.

During the period of the dementia strategy we will work with partners to bring the current material together in a way that is easy to use and which enables people to find the support that they need more quickly. We will also explore how we might expand what is currently available to improve the range of supports that are available, working with people with dementia, their carers and families, as well as staff, to understand their needs and expectations.

**COMMITMENT 9: We will work with NES, SSSC, NHS Health Scotland, NHS 24 and Alzheimer Scotland to develop and launch an innovative digital platform for dementia, which will help inform and empower people with dementia and their families and carers in being equal partners in care.**

### **Service response in hospitals**

Improving care in hospitals was the second of two key improvement areas in the first Dementia Strategy. Our challenge remains to ensure that, when admission to acute general hospitals is unavoidable for people with dementia, they experience, on every occasion, safe, effective, dignified and person-centred care.

The Midlothian Dementia Demonstrator showed that in 2008/9 that people with dementia accounted for 20.4% of the occupied bed days used by people aged over 65, even though they only accounted for 5.4% of the total population over 65. As the number of people with dementia increases, we need to do more work to understand why people with dementia are admitted to hospital and take more action on key areas such as unscheduled care, patient flow and delayed discharge.

Our objective is to do two things: to make the current system of care in hospital work better for people with dementia in ensuring better quality of care; and to begin to look at how we remodel the wider system of care, including care in hospital, to address how we best provide acute health care for people with dementia in a way which keeps them at home wherever possible and which ensures they are discharged from hospital safely and timeously. The wider context for this work is, of course, the integration of health and social care.

The last two years have seen significant investment in the capacity and capability of staff in hospitals, including the training of over 300 Dementia Champions in line with the skills framework set out in *Promoting Excellence* and the Scottish Government's support of the appointment to each NHS Board of an Alzheimer Scotland Dementia Nurse Consultant. In addition, some Boards have also appointed an Alzheimer Scotland Allied Health Professional.

These dementia specialists are making good progress and they support the prioritisation given by the Scottish Government to older people's care since 2011. This prioritisation has led to a number of actions, including: work on implementing the *Standards of Care for Dementia in Scotland*; the programme of inspections into older people's care in acute hospitals by Healthcare Improvement Scotland and resultant Board Action Plans; and the associated national Improving Care for Older People in Acute Care Programme led by the Chief Nursing Officer.

The Dementia Dialogue process included discussion of this key area of care and also included a national event specifically on care in acute settings. The messages that we heard during these meetings reinforce the need to retain hospital care as a key change area and to consolidate and build upon the work taken forward since 2010, but also to identify areas where additional support and leverage is needed.

### Implementing the Standards of Care for Dementia in Scotland in hospitals

In January 2012, an expert Dementia Standards in Hospitals Implementation and Monitoring Group (IMG) was set up, chaired by the Chief Nursing Officer and including representation from key partners such as Alzheimer Scotland, Healthcare Improvement Scotland, the Mental Welfare Commission, clinicians and healthcare services. A major part of this group's work has been to scrutinise all the evidence in relation to dementia care in hospitals in order to provide information on progress at a national level, to highlight and learn from examples of best practice and, where areas for improvement were identified, to provide expert support and guidance.

We have agreed a **10-Point National Action Plan**, developed by this group, to support implementation of the Standards of Care for Dementia in acute care to make sure the current system of hospital care is working and to maximise the impact of the investment over the last 2 years in the capability and capacity of staff operating in those settings. It will support service transformation and support strategic ownership of this agenda at an NHS Board level. The Action Plan will help focus and coordinate a range of initiatives taken forward over the last two years. The Action Plan's 10 headline areas have been developed over recent months by the National Dementia Standards in Hospitals Implementation and Monitoring group

**The 10 Actions are:-**

**1. Identify a leadership structure within NHS Boards to drive and monitor improvements**

**2. Develop the workforce against the *Promoting Excellence* KSF**

**3. Plan and prepare for admission and discharge**

**4. Develop and embed person-centred assessment and care planning**

**5. Promote a rights-based and anti-discriminatory culture**

**6. Develop a safe and therapeutic environment**

**7. Use evidence-based screening and assessment tools for diagnosis**

**8. Work as equal partners with families, friends and carers**

**9. Minimise and respond appropriately to stress and distress**

**10. Evidence the impact of changes against patient experience and outcomes**

We will develop a detailed delivery plan with the intention that the 10-point Dementia Care Action Plan is implemented over the next 3 years. The implementation plan will identify key deliverables, action leads and improvement support. It will align and integrate where possible with other existing national programmes and initiatives, such as the Person Centred Health and Care Programme.

**COMMITMENT 10: We will develop and deliver a 3-year National Action Plan to improve care in acute general hospitals.**

Implementation of the *Standards of Care for Dementia* and *Promoting Excellence* in other healthcare settings

Our focus under the first dementia strategy was on implementation of the Dementia Standards in acute general hospitals. However, a strong message from the Dementia Dialogue events was that similar attention in the future needs to be on other inpatient services, including NHS mental health services for people with dementia and rural community hospitals and in psychiatry of old age wards.

Some NHS boards have already begun to make use of mock inspections by adapting the approach used for inspections into care of older people and the pilot NES Supporting Change programme. While these settings share many of the wider strategic and organisational issues that acute general hospitals face, there are different and additional challenges and it is unlikely that care will always be of the quality required under the Standards of Care for Dementia, nor that staff will meet the expectations in respect of knowledge and skills set out under the *Promoting Excellence* framework. The Mental Welfare Commission will be considering the application of the Standards in this context as part of its visits programme in 2013-14.

**COMMITMENT 11: We will set out plans for extending the work on quality of care in general hospitals to other hospitals and NHS settings.**

## Care Homes

We know that there are challenges around the provision of care for people with dementia in care homes and that in the future care homes will increasingly be concerned with providing specialist care, including end-of life care, for people with dementia. A National Task Force has been established on the future of residential care in Scotland, to examine at a strategic level the key purpose and desired structure of residential care services fit for the aspirations and needs of future generations. The Task Force will produce a report with recommendations as to how to give effect to the reforms sought by autumn 2013. A strategy will then be drawn up and consulted upon during late 2013/ early 2014

There is more work to do around implementing *Promoting Excellence* so that care home staff are able to access the training available to help them improve care in the here and now. We know that there will be people with moderate to advanced stages of dementia in care homes but who do not have a diagnosis. We need to do more work to ensure that such people are identified in care home settings and that those diagnosed on or after 1 April 2013 receive the benefits of the new post-diagnostic commitment in a way that is meaningful and relevant to them in their particular care setting and stage of the illness.

**COMMITMENT 12: We will work with Scottish Care, SSSC, NES and others to assess the need for, and take further action on, improving service response around care homes, care at home and adult day care services. This will include attention to staff training and support for the implementation of the post-diagnostic HEAT target and the commitment on reducing inappropriate prescribing of psychoactive medication for people diagnosed in care homes.**

### **Reducing inappropriate prescribing of psychoactive medications**

The first Dementia Strategy identified that a key driver to ensure care and treatment is always safe, effective and appropriate is working with partners to reduce the inappropriate prescribing of psychoactive medication for people with dementia.

People with dementia are entitled to care that is appropriate to their needs at all times and in all care settings and which recognises, promotes and protects their rights and dignity, including safeguarding rights to safe and appropriate care and treatment; maximises their involvement and say in how care and treatment is delivered as far as possible; and helps people retain existing capabilities as far as possible. These principles underpin the dementia standards and the *Promoting Excellence* framework.

Last year we published the findings and recommendations of an report we commissioned into time trends in the prescribing of antipsychotic and other psychotropic medications to older people with dementia between 2001-2011. The report showed that, since 2009, there has been a decline in the initiation of new antipsychotics and a moderately decreasing trend in antipsychotic use. The report showed, further, that in the first quarter of 2011 the rate of older people with dementia being prescribed an antipsychotic was at the lowest level over the 2001-2011 period.

A Joint Royal Pharmaceutical Society and Royal College of Psychiatry Old Age Faculty Pharmaceutical Care for People with Dementia Expert Working Group has been asked:

To agree and recommend a national commitment on the prescribing of psychoactive medications (excluding cognitive enhancers), as part of ensuring that such medication is used only where there must be a likelihood of benefit to the person with dementia and where there is no appropriate alternative.

This is a short-life group, with a recommendation to be made to The Scottish Government in the summer 2013.

**COMMITMENT 13: We will finalise and implement a national commitment on the prescribing of psychoactive medications, as part of ensuring that such medication is used only where there is no appropriate alternative and where there is clear benefit to the person receiving the medication.**

### **Integration Outcomes**

National outcomes are being developed as part of the work to integrate adult health and social care. The Scottish Government will shortly consult on the draft outcomes designed to apply to all care groups and settings. While these high level draft outcomes will not make specific reference to dementia, local health and social care partnerships will need to apply them to services as part of their work in taking forward strategic commissioning and to demonstrate that people with dementia are benefitting from integrated services. The high-level outcomes will be supported by a suite of indicators and measures of quantitative and qualitative change and improvement and we will ensure that these appropriately reflect the needs and experience of people with dementia and their carers. Health and Social Care Partnerships will develop and take forward locality based implementation plans as part of the joint commissioning process.

**COMMITMENT 14: We will take account of the expectations and experience of people with dementia and their carers in taking forward the work on outcomes for the integration of health and social care.**

### **Research**

Supporting world-class research into dementia, including treatments and the delivery of care, remains a key part of our strategic approach to dementia. We recognise that people with dementia and their carers have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research. People with dementia and their carers can:

- bring their expert knowledge of how they experience the condition to the partnership with professional researchers;
- give voice to what they see as the priorities for dementia research; and
- become directly involved by participating in research.

The Scottish Government established the Dementia Clinical Research Network for Scotland from August 2008, with over £1 million of funding. This funding has been extended to 2014. The Scottish Dementia Clinical Research Network, together with

Alzheimer Scotland, seek to enable people with dementia and their carers to become partners in research, including the opportunity to participate in early studies of potential treatments.

We will build on the research achievements of the first strategy whilst continuing to affirm that people living with dementia have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research. The Scottish Government will:-

- strengthen research by continuing to support the Scottish Dementia Clinical Research Network to develop clinical dementia research capability and capacity.
- broaden support across a wide range of world class research teams from basic science through to social studies to integrate dementia research by working with the new Scottish Dementia Research Consortium to maximise the impact of and funding opportunities for research in Scotland.
- promote the use of world class Scottish Health Informatics, including record linkage, in dementia research.
- ensure that every person who is newly diagnosed with dementia is given the opportunity to be a partner in research.

### **The Scottish Dementia Research Consortium (SDRC)**

is a membership based organisation which aims to support the development and expansion of high quality, co-ordinated, collaborative dementia research throughout Scotland.

The SDRC is open to individuals who are engaged in and/or planning to engage

in research, in one of the four main fields of:

- Science and Technology
- Clinical, Health and Applied Practice Psychology and Humanities
- Social and Population

### **The SDRC's objectives are to:**

- Bring together Scottish-based dementia researchers from all disciplines
- Promote collaboration and co-ordination between researchers and
- enable a pooling of talent and skill
- Nurture a greater level of joint research applications and increase
- the level of national and international research funding secured by
- partners within the SDRC
- Represent Scotland's dementia research interests at a national, UK,
- European and international level
- Ensure that the voice and views of people with dementia and their
- families are central to research policy and development
- Ensure that there is an effective communication strategy with the
- general public about the level and scope of research

**COMMITMENT 15:** We will continue to support research through funding The Scottish Dementia Clinical Research Network and supporting the work of the new Scottish Dementia Research Consortium in its objective to bring together the range of dementia research interests in Scotland and maximise the impact of and funding opportunities for research capacity here.

## **Early Onset Dementia, Dementia as a Co-Morbid Condition and Equality Issues**

The majority of people who develop dementia do so in later life, but some people will develop dementia earlier, either as a single condition, or as a co-morbidity with another condition. The needs of these groups of people are different and services need to understand and work with that difference in the context of diagnosis, support, care and treatment.

There are five particular challenges that we want to focus on here, where a different approach or approaches may be required to ensure that people are able to achieve the same standard of outcome as others with dementia who are seen as more 'mainstream'.

**Early onset dementia:** While the overwhelming majority of people with dementia are over 65 years of age, there are around 2,500 people in Scotland who have early onset dementia. People coming to terms with the illness may need to be signposted to a distinct range of information and supports and have a reasonable expectation to receive care and support in age-appropriate settings. In addition, they are likely to have different needs in respect of post-diagnostic support.

**Learning disabilities:** People with learning disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age. Life expectancy of people with Down's syndrome has increased significantly and the incidence and prevalence of Down's syndrome is not decreasing.

**Other chronic conditions:** It is increasingly the case that people who have one chronic condition also have another or other chronic conditions, increasing the complexity of care and support. For those with dementia, this may be pre-existing or may develop after the diagnosis of the dementia. In either case additional care and support will be required to ensure effective management of the conditions.

**Sensory Impairment:** There are people who are likely to be living with a 'hidden and untreated' sensory loss, including people with dementia. There are also likely to be people with sensory impairment and dementia who cannot effectively access dementia services – including diagnostic and post-diagnostic services - because of that impairment.

**Black and Ethnic Minority communities:** Different patterns of engagement with health and social care services, while based on strong family structures, may make it less likely that people come forward for diagnosis or that if they do that they do so

later or engage with services differently. We need to ensure that how we engage and deliver services does not disadvantage this group.

**COMMITMENT 16:** We will undertake a brief piece of work focusing on the care pathway for people with dementia in these groups, through diagnosis and support, through treatment and care, taking account of the particular challenges for carers and family members with the objective of identifying what further actions are required to ensure that each of the key improvement areas – diagnosis, post-diagnostic support, care co-ordination requires modification to take account of the needs of different groups.

### Support Activity

Since 2008 we have provided national improvement support and expertise to help local services improve dementia services, initially focussing on supporting delivery of the HEAT diagnosis target. Over the course of the first Dementia Strategy we have provided integrated improvement support across local health and care systems, to help facilitate local whole-system change and evidence on the value and that support. Through 2012 we have supported the work of the post-diagnostic test sites in mapping and costing the new HEAT target.

During the Dementia Dialogue process, it was evident that services recognised that local systems need further redesign but that there was not always local expertise or resource to help facilitate that change.

We have therefore developed a **National Dementia Improvement Programme**, drawing on the blend of improvement support skills in The Joint Improvement Team and The Scottish Government Quality and Efficiency Support Team utilised in the Dementia Demonstrator and post-diagnostic test sites work, with a number of key improvement objectives over the next 3 years:-

- supporting the delivery of the **Post-Diagnostic HEAT target** across all Health and Social Care Partnerships across Scotland. Delivery of this target will require services to engage in significant redesign work
- testing the **Alzheimer Scotland '8 Pillars' model** for community based support in 3 or 4 pilots looking at different environments (urban; rural; island), but also within different hosting arrangements – primary care, local government and an integrated service
- working with colleagues **in primary care** to identify specific initiatives that can be taken forward to improve primary care services for individuals with dementia and their families
- testing initiatives around community capacity/**coproduction**
- supporting the **improvement work in general hospitals**

- working alongside the improvement work on **unscheduled care and patient flow** to ensure that people with dementia receive appropriate services based on their needs
- supporting partnerships to effectively use **data** to drive improvement in dementia health and social care services.

The National Improvement Programme is not designed to support implementation of the entire strategy, but will focus on certain key areas. Overall performance monitoring will involve a combination of monitoring implementation of the post-diagnostic HEAT target, scrutiny, implementation of the dementia standards, and publishing dementia benchmarking data.

We will also publish a **dementia benchmarking framework in 2013** to enable services to compare performance around key indicators of improvement.

### **Monitoring Implementation of the Strategy**

As in the first Dementia Strategy, there is a shared commitment to take forward transformational change, with the commitments designed to help deliver change across a range of service areas and organisations with different governance and accountability arrangements.

We will continue over from the first Strategy an Implementation and Monitoring Group, chaired by the Scottish Government and including representatives of key stakeholders from the statutory, voluntary and private sectors, the scrutiny bodies, as well as people who have dementia and their families and carers.

The Group's key tasks will be to:

- Ensure delivery of the Commitments, including being responsible for considering next steps in relation to particular Commitments.
- Monitor and track change and improvement over time in respect of dementia services. The framework will build on the benchmarking work set out above and where possible will be based on existing data sources or data which is provided through the benchmarking work. It will take account of items such as:
  - The number of people with a diagnosis;
  - The number of people receiving post-diagnostic information and support;
  - Reductions in unnecessary admissions to general hospitals and reduced period of admission for those for whom it is appropriate;
  - Reductions in the use of psychoactive medication;
  - Compliance with Part V of the Adults with Incapacity Act;
  - Increases in social and community activities, including physical activity; and
  - Improvements in the experience of people with dementia and their carers.
- Prepare an Annual Report on progress to be published in June 2014 and June 2015.

- Commission a revision of the Dementia Strategy, which takes account of progress and learning, to be in place from June 2016

The Group is likely to meet 3-4 times a year. It will publish progress minutes, papers and reports on the Scottish Government website.

The Implementation Monitoring Group is an additional national structure to look at overall implementation. It does not remove the requirement for there to be local progress monitoring and performance management and it does not change the existing accountabilities of statutory organisations. Its establishment is a recognition of the shared commitment to change and the fact that transformational change will only be possible as a collaborative process.

The Dementia Forum, which includes representatives of a wide range of partners, will continue to meet as a broad-based stakeholder group on a regular basis and receive reports on implementation of the Strategy.

**COMMITMENT 17: To oversee and ensure progress on the dementia agenda and in implementing this Strategy, we will carry over from the first Strategy an Implementation and Monitoring Group to co-ordinate, support and monitor progress on the other commitments outlined in this Strategy.**