Scotland’s National Dementia Strategy:

One Year On Report

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Ministerial Foreword

We published Scotland’s National Dementia Strategy almost exactly a year ago and this is the first annual report from the strategy’s Implementation and Monitoring Group, illustrating progress made over the last twelve months.

In concentrating the strategy on 5 key challenges – including its two key improvement areas of post-diagnostic support and improved service response in general hospital and eight key supporting actions, we are working with our partners in a very focussed way. This approach is designed to drive and deliver tangible and measurable change and improvement in dementia services over an initial three-year period.

The end of year one of the strategy’s implementation is marked by the publication of two major documents: Standards of Care for Dementia in Scotland and Promoting Excellence.

Standards of Care is designed to empower those with dementia and their families and carers in asserting their rights; to inform the commissioning and provision of services; and to inform scrutiny and inspection of services. The standards articulate our national consensus on what level of quality those with dementia should expect in local services and we will engage in national and regional consultation on their contents and on how they translate into practice.

Promoting Excellence delivers a comprehensive skills and knowledge framework for all health and social care staff and its large programme of implementation includes updating professional qualifications and targeted educational initiatives in key care areas.

Transforming dementia services is one major part of our wider shared endeavour to reshape care for older people. Key to this endeavour will be the delivery of an integrated system of health and social care across Scotland – to ensure that our older people are at the centre of service delivery. This process is already underway, with the Change Fund helping local service redesign around more personalised, community-based, anticipatory and enabling and re-enabling principles.

The Dementia Strategy is playing an important role in moving the wider agenda around older people’s services forward; its success over the next two years will be extremely important in demonstrating how integrated services can deliver better quality of care for those with dementia and their families and carers.

NICOLA STURGEON
Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy
1. Common Standards of Care for Dementia

1.1 One of the strongest messages repeatedly coming out of the development of the strategy was a demand and need for a greater common understanding of what constitutes a good quality of care and support – through all stages of the illness and in all care settings. The nature of the illness means that people quite often have difficulty in asserting their rights in demanding quality; and they and their families and carers can be subject to discrimination which means that they can be treated with less dignity and respect than other members of society.

1.2 The final strategy reflected this key message in committing to the development and implementation of common standards of care for dementia. In doing so, the strategy adopted the principles of the Scottish Parliament’s Cross-Party Group on Alzheimer’s Charter of Rights for People with Dementia and their Carers in Scotland, which stated that, in line with their human rights as enshrined by law, people have the right to be empowered to participate fully in the design and delivery of care to live as independently as possible, and be free from any discrimination.

1.3 The Scottish Government commissioned The Mental Welfare Commission to lead in developing the standards, with a multi-representative steering group Chaired by the former Director of the Dementia Services Development Centre, Professor Mary Marshall and including people with dementia and carers. The steering group met regularly over almost a year to guide the preparation of the final document. Its content, as it was developed, was also consulted on in a series events held throughout Scotland.

1.4 The final document is designed to help people with dementia and their carers understand and assert their rights in obtaining and participating in care and treatment which they need. It is designed as a key resource for those statutory and voluntary agencies providing services in giving detailed information on what is expected from them in terms of the content and quality of services; and for NHS Boards and local authorities in assessing the services commissioned or managed. For scrutiny and improvement organisations, it will inform the assessment of care in individual cases and in programmes of inspections.

1.5 The standards explicitly assert that people have a right to a diagnosis; the right to be treated as a unique individual and to be treated with dignity and respect; the right to access the range of care and treatment; the right to live as independently as possible and be included in the community; the right to have carers who are well supported and educated about dementia; and the right to end of life care that respects their wishes. For each of these, the standards describe what should happen in individual’s care and treatment in order for this right to be promoted, recognised and protected – and the role to be played by agencies in order to ensure that the standards are implemented every time.
1.6 The standards articulate a national consensus on what level of quality those with dementia should expect in local services. While we will expect services to use the standards in an early assessment of local provision – to identify areas of strength but also areas where changes and improvements need to be made - we will simultaneously, over the best part of the next year, engage in national and regional consultation on their contents and how they translate into practice.

2. Skills and Knowledge Framework

2.1 In developing the strategy, it was clear from the working groups and the consultations was that improving staff training around the particular needs of those with dementia would be hugely important in transforming services.

2.2 The final strategy said that improvements in staff response is needed throughout the health and social care system, and in particular in relation to the strategy’s two key improvement areas; improvements not only in knowledge about dementia but also in awareness of the need to promote and protect individuals’ rights and dignity. From diagnosis and as the illness progresses staff should always be facilitating the co-production of care, in doing so sustaining independent living as far as possible. Staff in general hospitals and Accident and Emergency units often have a poor understanding of the needs of those with dementia (and of their families and carers) and addressing these knowledge and skills gaps would greatly improve care and outcomes. Similarly it would be possible to reduce the number of inappropriate admissions from care homes into general hospitals with better training for staff in long-term care settings.

2.3 Promoting Excellence is the result of nearly a year’s work commissioned from NHS Education Scotland and the Scottish Social Services Council. The work was overseen by a Programme Board chaired by The Chief Executive of Alzheimer Scotland, Henry Simmons and comprising the range of interests, including people with dementia, carers and professional groups. The project was developed in parallel with the development of the standards and there are through both documents synergies and explicit linkages made.

2.4 The project began by establishing a common understanding of what the baseline of knowledge and skills should be for each particular job description in relation to dementia. The final framework is for all staff who have contact with and provide support for people with dementia and will be used in conjunction with pre-existing knowledge and skills frameworks relevant to particular care sectors and groups. It defines 4 levels of knowledge and skills, from baseline knowledge and skills required by all staff working in health and social care settings through to an expert level for staff who have a specialised role in dementia services. It defines stages in the journey of people’s experience of dementia and describes ways in which staff can utilise quality of life indicators – mapped across to the standards - to measure the impact of a changing approach in the workforce in providing dementia services.
2.5 The framework’s implementation over the next 2 years includes updating professional qualifications; revising and developing vocational qualifications; disseminating knowledge and learning; developing leadership capacity and integrated workforce capability within existing services; and targeting educational and ongoing training resources in key areas and settings.

2.6 There will be a key role for the third sector and with service users and families and carers in much of this activity; for example in focussing on workforce improvement activity it will be important to work with Alzheimer Scotland advisers and nurses; and with The Scottish Dementia Working Group, whose work of course directly reflects the experience and expertise of those with dementia.

3. Integrated Support for Change

3.1 The strategy recognises that key to improving dementia services will be the transformation of health and social care services - towards an integrated, cost-effective whole-system approach which shifts the emphasis from high-cost long term care settings to preventative and community-based services which are co-produced by those with dementia and their families and carers.

3.2 The Dementia Demonstrator Sites project looks to demonstrate the benefits of this approach and influence the wider agenda on fundamentally reshaping care for older people. Its ambition is to provide an example of how national improvement support for both incremental and step-changes across all sectors can be effective in supporting the streamlining, integration and outcomes-focus of entire local systems; and to produce an economic analysis of the impact of these changes.

3.3 While the strategy said that it would support one demonstrator site, the level of interest in and quality of applications from local partnerships persuaded us to select 3 sites. Eleven initial applications were received from which the successful sites – Perth and Kinross, Midlothian and North Lanarkshire – were selected. Selection was on the basis of the strength of their applications and because the 3 sites also represented a geographic and social spread, with, for example, the relative deprivation and long-term unemployment in North Lanarkshire contrasting with the more rural and more relatively affluent areas of Midlothian and Perth and Kinross. Following the finalisation and agreement of project plans and the putting in place of national support and a governance structure, the project formally began in early 2011 and will run for fifteen months.

3.4 The final project plans capture ongoing and planned local activity within the 3 sites – such as early identification, enablement support, the implementation of integrated care pathways and the strengthening of intermediate care - designed to help drive a shift away from institutional care and from unnecessary admissions into acute care; and to align with the key challenges identified by the national strategy. All projects adopt a local outcomes-focussed approach to assessment, care planning and review; and associated local activity includes consideration around issues like housing and transport.
3.5 Key to the success of the project will be its evaluation and here the role of national support is important. As part of the evaluation, all 3 sites are using the cost-consequence analysis model, which will capture all the relevant costs (resource use) and the non-financial consequences such as improvements in patient satisfaction and improved quality of care. The evaluation will also measure outcomes based upon core common indicators used by the 3 sites aligned with the national dementia benchmarking framework. In addition, the sites agreed to develop a common approach - in working with the third sector and others - to an ongoing assessment for individuals during the progress of their dementia using the Talking Points model. This individual support would be aggregated and continued over time as part of sustaining activity beyond the immediate life of this project.

3.6 Working relationships between the 3 sites are being maintained by monthly meetings with the site project leads, and other meetings as appropriate, the results of which are fed back to the project’s core governing group. A strategy for spreading learning from the project is being finalised; and a national learning event is planned for this autumn, to assist all of those involved in this strand of the strategy to reflect on and share further activity and learning up to that point.

4. Improved Management and Outcome Information

4.1 The strategy recognises that, as part of providing integrated support for change, improved local and national information systems are required to help service providers, those receiving services and those scrutinising services to see the impact of the strategy’s implementation on local outcomes and efficiencies; and on a national level in enabling an accessible and transparent comparison of services. The dementia benchmarking work is also forming the basis of the strategy’s monitoring framework which will track change and improvement over time and in doing so inform the work and oversight of the strategy’s Implementation and Monitoring Group.

4.2 When developing the strategy there was a broad consensus that, while there were some good sources of outcomes information, for example in relation to the HEAT target and the dementia Integrated Care Pathway (ICP), more consistent information was needed throughout dementia services and at all stages of the illness.

4.3 This work has been taken forward overseen by a benchmarking group (including statisticians and analysts from NHS National Services Scotland information division), with the group and subgroup meeting to work up a draft dementia balanced scorecard, or benchmarking framework. The scorecard is structured in alignment with the 5 key challenges identified by the strategy, including its two key improvement areas – post-diagnosis support and improving service response in general hospital. This work should be completed in the early autumn.
4.4 Within each area of the scorecard, data presented will utilise pre-existing health and/or social care data sets, such as the Quality Outcomes Framework (QOF) dementia register; data related to ICP standards including on matched interventions and on advanced care planning; and care home and general hospital registers. By way of example, in the section on post-diagnosis support data will be drawn from the generic ICP data on the requirement to record a diagnosis and from QOF register on the percentage of dementia patients who have had a clinical care review in the previous fifteen months. The section on general healthcare services will draw on data on admissions, readmissions, length of stay, the number of ward transfers and on discharges – but this part of the dementia benchmarking work presents more challenges in reading and interpreting data due to the under-recording of dementia as a secondary cause of admission in general hospital settings.

4.5 With regard to accessing pre-existing data sets collected from social care services, the dementia benchmarking group have also linked their work with the review of the Community Care Outcomes Framework to explore including additional data in the final scorecard as indicators or proxy indicators, for example data relating to over-65s receiving care at home.

4.6 Rather than extending the reach of the dementia benchmarking work into collecting data on the range of areas such as housing, environment and transport as indicators, the benchmarking group have refined their remit so as to focus the scorecard around areas where the dementia strategy can demonstrably effect change.

5. Continued work on Diagnosis

5.1 The Dementia Strategy recognises that diagnosis is important as it is a gateway to effective care and support. The person who has been diagnosed with dementia, and their family, now know the cause of the changes that have worried them. They have a chance to get back in control of their lives by understanding their condition, what the future might hold and make plans accordingly. They may be able to start drug or psychological treatments or take part in research projects, none of which they would be able to do without a dementia diagnosis.

5.2 Since 2007 the NHS in Scotland has worked to increase the number of people who have a diagnosis of dementia. Our aim was to increase the number of people registered in primary care with a diagnosis of dementia from 29,603 in March 2007 to 39,578 in March 2011. The data is only published annually and therefore the following chart shows data up to March 2010. The position for March 2011 will be published in September 2011 and we anticipate that, at a Scotland wide level, this target will be met and exceeded. Individual Health Board positions will also be available when the data is published in September 2011.
5.3 As well as actions to deliver increases in the number of people diagnosed, there have also been significant improvements in the early management and support provided post diagnosis. Different areas have prioritised different initiatives but some of the key pieces of work have included:

- delivering training to GPs, general hospital staff and care home staff on how to recognise the symptoms of dementia and how to provide dementia friendly care.

6. Better response to behaviours that staff and carers find challenging

6.1 The strategy aims to ensure that people with dementia receive care that is appropriate to their needs at all times and in all care settings and which recognises and protects their rights and dignity, including safeguarding rights to safe and appropriate care; maximising their involvement and say in how care and treatment is designed and delivered as far as possible; and help people retain existing capabilities and skills as far as possible.

6.2 When developing the strategy through 2009 it was clear that these principles were key to improving care and treatment when managing behaviour that challenges – in particular when prescribing psychoactive medication. The Mental Welfare Commission published *Remember I’m Still Me* in 2009, which told us that people in care homes were often receiving impersonal care and that, as part of that culture, there was an overuse of such medication; and the strategy included an expert working group tasked with looking at this area of care in all care settings.
6.3 As part of improving care and treatment in this area the strategy makes a commitment to a reduction of the use of psychoactive medication during 2011 (and a further reduction for future years). This commitment is designed to help drive wider changes such as involving those with dementia and their carers in promoting positive care in order to help behavioural issues from arising; always exploring therapeutic approaches as the first alternative in intervening in such circumstances; always regarding the use of psychoactives as the last treatment option and complying fully with the law in assessing someone’s capacity to consent to treatment; and always reviewing prescribing at regular intervals to assess its continued appropriateness.

6.4 In preparing the framing of the initial commitment on reducing prescribing this year, we have commissioned a specialist academic baseline assessment on the current use of psychoactive medication for those with a diagnosis of dementia. It is tasked with looking specifically at the prescribing of antipsychotics and other psychoactive drugs to people over the age of 65 with dementia over the last decade – compared to such prescribing to over-65s without dementia. This also includes assessing any evidence of changes in prescribing practice in response to regulatory warnings; and, importantly, the duration of such prescribing in each case.

6.5 Clinical decision-making in individual cases is of course taken by the relevant professional, and there are cases when the prescribing of psychoactive medication is appropriate and the best treatment option at that particular time, particularly when psychotic symptoms manifest themselves in behaviour which cannot be managed without medication. We know for example that such drugs may be helpful for some in relieving symptoms such as agitation, delusions or hallucinations, and, although there are risks, where the prescribing of psychoactive medication is appropriate, clinical decision-making will always need to weigh any risk against the risks around not prescribing.

7. Accelerated Implementation of the Dementia Integrated Care Pathway

7.1 The strategy said that we will improve the management of care for people with dementia through faster implementation of the dementia care pathway, with a particular focus on diagnosis and responding to behaviour that people find challenging.

7.2 As part of this we said that during 2010/11 NHS Boards would start to collect data in relation to particular components of their local care pathways in order to accelerate implementation of the dementia Integrated Care Pathway (ICP).

7.3 An ICP sets out the process of assessment, care and treatment for service users with similar diagnoses or symptoms. It lets service users know what they should expect from services. It should set expectations for the local management and organisation of care and act as a point of comparison for treatment and care
provided. A good ICP will look beyond treating the disorder and will focus on the full range of needs and capabilities of the individual.

7.4 The dementia ICP standards focus on key elements of the dementia journey:
   - post-diagnostic support;
   - assessment for therapies; and
   - managing challenging behaviour.

7.5 NHS Healthcare Improvement Scotland is developing an implementation plan for Integrated Care Pathways to support NHS Boards to develop their ICPs locally. They are developing operational definitions for a small number of key data points that NHS Boards across Scotland will be asked to collect. This will include recording information about diagnosis, what information has been provided to the service user, and what support has been offered after diagnosis. Definitions are also being developed about assessment of suitability for a psychological therapy, including for people with dementia.

8. Continued Action to support dementia research

8.1 The strategy continues the Scottish Government’s commitment into research into the medical treatments for dementia and the delivery of care, in doing so using the experience of people with dementia and families and carers in informing this work.

8.2 The last year has seen dementia research in Scotland gaining increasing momentum. This has been aided by the continuing support by the Chief Scientist Office of the Scottish Dementia Clinical Research Network (SDCRN). This support has been extended to March 2012. The SDCRN now covers Health Boards from the Borders to Highland and from Ayrshire to Grampian. There are also ongoing discussions to include people from the Northern and Western isles. The number of studies adopted by the SDCRN has grown exponentially and the aim of attracting matching external funding has been met and exceeded. The SDCRN has also been pivotal in attracting commercially-sponsored multi-centre trials to Scotland.

8.3 Together with Alzheimer Scotland, the SDCRN conducted a questionnaire of what people, including a substantial number of people with dementia, considered to be the priorities for dementia research in Scotland. This will be seminal in informing the future direction of dementia research in Scotland over the next few years.

8.4 Scotland is showing leadership in developing a national research register of people with dementia and carers. The target to recruit 1,000 people to the register was comfortably surpassed. The availability of this register has been an important driver of clinical research and is now being emulated in England and Wales. The register is also a major mechanism for people with dementia and their carers becoming directly involved in research. People on the register are being
contacted to take part in research specifically suited to them, and give permission for their register details to be linked with an internationally renowned state-of-the-art health informatics systems which will enable researchers in Scotland to understand far more about how people with dementia use health services.

8.5 Scotland has world-leading basic scientists, not a few of whom are engaged with dementia research. Examples include working out how stress hormones affect memory centres in the brain, which may lead on to important treatments for conditions like Alzheimer disease. Investigations into how diseases of the blood vessels can lead to memory problems are also high on the agenda.

8.6 Overall, not only do Scottish scientists remain at the forefront of dementia research, but the people of Scotland by joining the Scottish Dementia Research Interest Register and signing up to take part in studies are just important in leading the way in this key area of the strategy.

9. Additional Activity

Specialist Dementia Nurses and AHPs

9.1 In January 2011 the Scottish Government announced that it would provide one-off funding of £300,000 to support Alzheimer Scotland to build on their pilot of specialist dementia nurses in NHS Boards. Their role is to support significant changes and improvements in the standards of care which people with dementia and their families receive while in acute general hospital, through specialist advice on care delivery, information, training and support. Evaluation of existing posts has provided clear evidence of the benefits of these posts, with gains in the quality of care and the safety for people with dementia; and benefits in terms of physical healthcare needs whether in care homes, at home or in hospital.

9.2 This funding, alongside an equal amount of funding by Alzheimer Scotland, is facilitating seven new posts for a guaranteed two year period in NHS Boards across Scotland. Negotiations are currently taking place with all NHS Boards to prioritise bids. It is anticipated that the postholders will be in place by late summer 2011.

9.3 This initiative adds to a number of local initiatives, all of which are helping to build a body of expertise in the area of the care of people with dementia in acute general hospitals. In order to further develop the evidence base in this key area, as part of implementing Promoting Excellence the Scottish Government has provided funding to NHS Education for Scotland to establish a national development programme and learning network for these posts focussed on leadership and change agent development, action learning and impact evaluation against the post outcomes.

9.4 In addition, in 2010 the Scottish Government supported the appointment of the first AHP Consultants in Dementia Care in 3 NHS Boards. Their role is to support the strategy's two key improvement areas.
BIG Lottery

10.1 In March 2010 the BIG Lottery in Scotland announced its intention to create a new fund of £50 million to produce a fundamental improvement in outcomes for young people leaving care and for older people with dementia and their carers, which will focus on improving post-diagnosis support. Over the last twelve months BIG has been putting in place the governance and accountability structures which will facilitate bids and manage and oversee the use of this funding. This process will be finalised in coming months.

Dementia Forum

11.1 The Dementia Forum, which has been Chaired by the Minister for Public Health pre-dates publication of the strategy but continues in its function of providing a forum for a wider, multi-representative network of dementia stakeholders to share views and engage with this agenda. It met most recently in early 2011 and will meet again later this year.

Implementation and Monitoring Group

12.1 Progress in implementing the strategy is monitored by this group. It met 3 times over the last twelve months and minutes of the meetings can be found here http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia