

30 September 2009

THE NATIONAL DIALOGUE ON DEMENTIA: DEMENTIA STRATEGY CONSULTATION PAPER

Dementia is a priority for this Scottish Government. Much has already been done to improve dementia care in Scotland, yet there is much more we can do. Earlier this year we made a commitment that we would develop and publish a Dementia Strategy for Scotland by April 2010. We already have workstreams taking this forward, and also as part of the commitment we said we would publish a consultation paper to encourage and support engagement by the wider community.

This is attached below and invites you to help shape the future of dementia services in Scotland by offering views, by **Monday 16 November**, on the work currently underway and planned to take this forward.

You will see from this paper that the workstreams cover all aspects of dementia in Scotland:

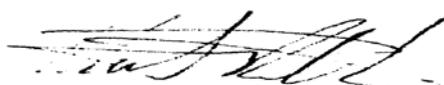
- 1) Treatment and Managing Behaviour
- 2) Assessment, Diagnosis and Patient Pathways
- 3) Improving the general service response to dementia
- 4) Rights, Dignity and Personalisation
- 5) Health Improvement, Public Attitudes and Stigma

Many of you may have a specific workstream that you are interested in. We are also keen to receive responses from organisations and individuals whose interests cut across all the workstreams; or who feel that their interests are perhaps not captured within the remit of the existing workstreams. We have also offered questions that we would like you to answer.

This is an important priority for this Government and the Dementia Strategy will frame and be the driver of its policy on dementia. I do hope that you will take this opportunity to help shape the future of dementia services in Scotland and I look forward to receiving your views.

Please feel free to share this with all with an interest in this important agenda. It is also available on: <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/latest>.

Yours sincerely



MARTIN ROTHERO

THE NATIONAL DIALOGUE ON DEMENTIA

Dementia Strategy Consultation Paper

September 2009

Ministerial Foreword

One of the first commitments that this Scottish Government made was that dementia would be a national priority. Dementia will affect an increasing proportion of the Scottish population over time, both those with the illness and those who are there to give them care and support. For too long it has been neglected with insufficient attention to the illness and expectations of service quality and support which, are too low. That must change.

We took immediate action in 2007 to make our commitment a reality. We established a national target to increase the number of people in Scotland with dementia who have a diagnosis, which we know improves access to treatment and care. We are piloting work on post-diagnostic support to get a better understanding of how we can deliver the services that people say that they want in the way that they want to receive them. We have tested new ways of improving public awareness of dementia, with the objective of encouraging people to seek help earlier. We have also increased the funding for research into dementia. We have continued to take forward the continuing work on integrated care pathways, with local pathways now achieving the first stage of accreditation.

While we have achieved much since 2007 and these are just some of the things we have done, we know that there is much more to do. The Care Commission and Mental Welfare Commission report "Remember, I'm still me" was a stark reminder of the chasm that often exists between the best care and the care that people receive.

Earlier this year we made the commitment that we would develop and publish a dementia strategy for Scotland and that we would complete that work by April 2010. We have established a series of workstreams to take that work forward and are continuing to work with the Dementia Forum which was established in 2007 to provide me with expert advice.

As part of that work we said that we would publish a paper for consultation by the end of September 2009 to support engagement with a wider community. This is that paper. It is intended as a focus for discussion and engagement over the coming months and we will be arranging local and national events to take that discussion forward. We are also keen that others hold their own events and discussions and that they feed the outcomes of those events into the national process.

When I met with the Dementia Forum in August I invited people to actively engage in the development of the strategy and to be creative about the possibilities of what can be achieved in providing quality services for people who have dementia. We have to think about where it is that we want to see improvement and how that improvement can be secured. Dementia services are already one of the highest areas of health and social care spending in Scotland with estimates of public sector spending being in excess of £1 billion per year. But we have said that we will pay proper attention to the resources that are required to secure the changes that we desire to deliver and that continues to be the case, even within the current challenging financial circumstances. This work needs to be linked to other work that the Scottish Government is taking forward with local government and other partners to rethink the structure of social care for the future.

I value your contributions into this paper; this process will be a key part of informing the national strategy as it develops through to publication in April 2010.

Shona Robison MSP

Minister for Public Health and Sport

Introduction

Dementia is an illness that usually develops slowly. It causes impaired memory, thinking and judgment. It predominantly affects those over 60 and is a major cause of disability for elderly people. As people live longer, more people will be affected by it. We project that the number of people with dementia will increase from around 70,000 in 2009 to 127,000 in 2031. The number will be close to double in just over 20 years.

Nearly every person who has or develops dementia will have a partner, children and friends, whose lives may also be transformed by the onset of the illness. It is estimated in work done by the European Union that, for each person with dementia, on average three other people are directly affected. It is a life-changing event for everyone who is concerned with their care. The illness will affect all of us, either directly or indirectly.

People with dementia require a range of services over the course of the illness, from initial information and support following diagnosis, to more intense treatment and care in the community, and to residential and long-stay care in some cases. The cost of that care is not insignificant. Alzheimer Scotland suggests that the overall cost of dementia in 2007 was between £1.5 billion and £1.7 billion, which is an average of £25,000 per person per year. Those figures include the costs of national health service and social work care, housing and the significant and valuable informal care that is provided by family and friends.

Work in place already

The Minister in her foreword has set out some of the main drivers for change which are in place. Those approaches are already beginning to have an impact on the way that services are being delivered and are receiving support from the Mental Health Collaborative through national, regional and local approaches and systems. In particular the work on integrated care pathways and on delivering the increased diagnosis target is leading to local initiatives including:

- the use of HoNOs 65+ clinical outcome measure in some NHS Board areas, These are 12 scales that are used to rate older adult mental health service users. Together, they rate various aspects of mental and social health, each on a scale of 0-4. They are designed to be used by clinicians before and after interventions, so that changes attributable to the interventions (outcomes) can be measured;
- the creation of a “dementia champions” network in one NHS Board to enhance knowledge and expertise of staff in acute hospitals;
- ongoing work in a number of areas in respect of memory clinics;
- local treatment algorithms being implemented; algorithms are used for calculation and data processing and provides a well defined list of instructions for completing a task;
- process algorithms being developed for matched interventions for people who develop behavioural or psychological symptoms, including the use of a challenging behaviour scale (CBS) and antecedent, behaviour, consequence (ABC) checklists or behaviour diaries;
- NHS Boards running workshops for staff on end of life care issues.

Broadening the scope of certain aspects of the local Dementia integrated care pathways may be a useful vehicle for implementing the dementia strategy, once it is developed.

Work underway to support strategy development

The work to develop the strategy is already well under way, with five workstreams that focus on different aspects of the improvement challenge that we face.

The Structure for ensuring the development of the strategy consists of the Dementia Forum who meet bi-monthly and will discuss the strategy as well as monitor its progress. A Dementia Strategy Management Group has been established and will meet monthly to consider the work being taken forward by the workstreams. This group will also be responsible for co-ordinating activity between the workstreams and ensure progress is being made.

The five workstreams have a mixed membership of professionals, who have an expertise in the areas their workstream is covering, service users and carers. The workstreams have all met at least once and are planning to meet on a monthly basis. A list of all agencies involved in the workstreams is included in Appendix 1.

An outline of the work that each of the workstreams is engaged in is set out below. There are overlaps between the work of the different workstreams and as indicated above the Management Group will seek to co-ordinate that activity. Equally, the strategy will need to cover issues not addressed by the workstreams as constituted – that is one of the purposes of this consultation.

Workstream 1: Treatment and Managing Behaviour

The first workstream is considering how we can offer effective treatment and manage challenging behaviour without inappropriate recourse to anti-psychotic medication. The workstream directly responds to the issues that were raised in the "Remember, I'm still me" report, which was published earlier this year by the Scottish Commission for the Regulation of Care and the Mental Welfare Commission for Scotland. It will also consider the effective implementation of part 5 of the Adults with Incapacity (Scotland) Act 2000, which the Parliament passed to protect the rights of those who lack capacity.

Prescribing and medication management – focusing on the need to improve liaison between General Practitioners, psychiatrists, nurses, community pharmacy and care homes and in community setting in respect of the use of medication, including record keeping.

Implementation of Part V of the Adults with Incapacity Act – focusing on both the appropriate completion of the paperwork and the quality of the information and planning under AWI as well as considering linkages with other related legislation.

Responding effectively to challenging behaviour – considering the range of approaches that can be taken to support behaviour management, including the appropriate use of medication, and to consider skills, training and decision making.

Workstream 2: Assessment, Diagnosis and Patient Pathways

The second workstream focuses on assessment, diagnosis and patient pathways. It builds on the work that is already under way in taking forward integrated care pathways for dementia and the work that is being pursued with health boards and general practice on early diagnosis. It considers both the different services that will be required by a patient over time and the process by which they move through the system.

Early diagnosis and response to dementia – including through post-diagnostic support, advance planning and information and support for carers.

Developing and managing the patient pathway – considering the patient journey drawing on the work that is already underway in relation to care pathways and including through community, care home and hospital care and end of life, including palliative care.

Range and quality of dementia support in the community.

Managing transitions – including admission and discharge from services, responding to crisis and delayed discharges.

Workstream 3: Improving the general service response to dementia

The third workstream will consider the general service response to dementia when people with dementia come into contact with general health services. We know that accident and emergency services can respond poorly to people with dementia and that people with dementia are more likely to be admitted inappropriately. Similarly, the care that people with dementia receive in general hospital settings is not always of the standard that we would like it to be. We believe that we can improve systems, skills and knowledge and, through those improvements, produce better outcomes for people with dementia.

Managing dementia in general hospital and other non-specialist settings.

Developing the skills and knowledge of the non-specialist workforce – including those in, A&E, GP practices, etc both through training and specialist support approaches.

Workstream 4: Rights, Dignity and Personalisation

The fourth workstream focuses on rights, dignity and personalisation. It is a key area for improvement, as it brings together both the legal context and the culture and behaviours of the people who provide care and treatment for those who have dementia. Our objective is to improve the knowledge and understanding of those who provide services so that they are better able to maintain people's dignity and provide more humane care and treatment. We want to embed the idea of personalisation into services, so that people will continue to see the person and not the disease. We also want to explore how we might use standards more effectively to promote quality improvement and how we can use the new scrutiny arrangements in the Public Services Reform (Scotland) Bill and the arrangements that will be brought forward under the proposed patients' rights bill to secure better outcomes for those who have dementia.

Promoting dignity and person-centred care – improving the knowledge and understanding that those providing services have about people with dementia and using that information to maintain the dignity and humanity of care and treatment. Examining how we can embed the personalisation agenda in our work on dementia. Thinking about the behaviours and cultures of health and care staff in responding to dementia.

Considering the standards of service delivery in place for those with dementia – and the methods and approaches in place for the improvement of the quality of care.

Considering the arrangements for the protection of rights for those with dementia and the application of the Millan Principles.

Promoting physical and social activity for those with dementia – both in care homes and in other care settings.

Workstream 5: Health Improvement, Public Attitudes and Stigma

The fifth workstream is consideration of health improvement, public attitudes and stigma. We know that some health improvement activities that people can engage in, such as taking exercise and being careful about what they eat and drink, reduce the likelihood of developing some, although not all, forms of dementia. We also know that work on the physical health of those who have dementia will improve both their life expectancy and their quality of life. Beyond that, the work on stigma and public awareness will contribute to the creation of a society in which those who have dementia and their carers are not shunned, ignored and misunderstood but regarded with respect and compassion.

Health improvement activity – focused on lifestyle changes which are likely to reduce the incidence and slow the progress of some forms of dementia.

Physical health checks and interventions for people with dementia alone or with other conditions to improve the quality of life.

Public attitudes work – to raise awareness and increase the number of people likely to seek help early.

Improving understanding of dementia – to make people more aware of the nature and challenges of dementia to improve the response to those with dementia.

How to respond

We offer five questions that we would find it helpful if you could answer.

1. Is there anything that you consider we have yet to include for consideration in the work underway by the 5 Workstreams?
2. Is there anything else we have yet to include - that maybe does not fit into the remit of the 5 Workstreams?
3. What do you think should be our main priority/or set of priorities?
4. What do you think is a realistic timescale for implementing any recommendations?

5. What do you consider you or your organisation could do to help make improvements in services for people with dementia, or in other areas such as awareness-raising?

Timetable and how responses will be dealt with

As previously stated the Dementia Strategy will be published by the end of April 2010. The workstreams will continue to meet at least monthly to complete the task.

Your written responses should be sent by email to Ravinder.Carothers@scotland.gsi.gov.uk at the Mental Health Delivery and Services Unit, the Scottish Government by Monday 16 November.

For those who wish to respond and do not have access to electronic mail, please send these to:

Ravinder Carothers
Mental Health Delivery and Service Unit
Room 3.ER,
St Andrews House,
Regent Road,
Edinburgh,
EH1 3DG

Responses will be channelled into the appropriate workstream for further discussion.

If you just want to know more about the dementia strategy or kept informed of its progress then please do not hesitate to contact me.

Further copies of this paper is available at:

<http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/latest>

Appendix 1 - Agencies involved in workstreams

Age Concern and Help the Aged Scotland
Alzheimer Scotland
Angus Council
Association of Directors of Social Work
Care Commission
COSLA
Dementia Research Network
Dementia Services Development Centre
Director Scottish Dementia Research Network
JIT Action Group
Mental Health Foundation
Mental Welfare Commission
NHS Dumfries and Galloway
NHS Greater Glasgow and Clyde
NHS Health Scotland
NHS Lanarkshire
NHS Lothian
NHS Quality Improvement Scotland
NHS Tayside
North Lanarkshire Council
Queen Margaret University
Royal College of Nursing
Royal College of Psychiatrists
Royal Pharmaceutical Society
Royal Victoria Hospital
Scottish Care
Scottish Dementia Working Group
Scottish Government
Scottish Mental Health Pharmacy Strategy Group
Scottish Partnership Forum
Scottish Recovery Network
SDWG
See Me Scotland
Social Work Inspection Agency
Stirling University
Stobhill Hospital
SWIA
The Neurological Alliance of Scotland
The Stroke Association
The Medical and Dental Defence Union of Scotland
University of Edinburgh

Dementia services users and carers are also represented on each of the five workstreams.