



LOTHIAN DEMENTIA PROJECT

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A proposal from Alzheimer Scotland and the Dementia Services Development Centre at the University of Stirling for 'practical solutions for deliverable and effective post-diagnosis support services, to be piloted in three NHS Board areas (Greater Glasgow and Clyde, Shetland and Lothian), to commence within 2008-09' has been accepted by the Scottish Government.

This is a three year programme which will help the achievement of the Scottish Government HEAT targets, through better support of people with a diagnosis of dementia, immediately after diagnosis, and this paper describes the service improvement deliverables to be achieved through an improvement pilot and the potential benefits that a phased-in model could deliver. This work will also be supported and complemented by the flow within the Mental Health Collaborative concerned about the achievement of the dementia HEAT target.

Specific Scottish Government targets related to this programme

The overall goals of the programme are outlined within the context of achieving the targets set out in respect of the Scottish Government Performance targets, the QOF targets, and the implementation of the standards for the ICP for dementia recently published by NHSQIS, and generally the new emphasis on dementia as a national priority.

Current issues

There is evidence that people with dementia have a mixed experience at the point of diagnosis. There are some excellent examples of good practice, but the lived experience of a number of people is that they are given very little support, and that staff do not think that it is their job or are not trained in how to go about this.

Encouraging the development of better integrated systems is a key feature of policy imperatives across older people's services over a long period. The 2005 framework *Better Outcomes for Older People*¹ states that 'the whole system approach puts the older person at the centre of all service delivery and planning. It provides the right support, at the right time by addressing the entire range of their needs'. The 2005 Audit Scotland review of delayed discharges comes to a similar conclusion, stating that 'delayed discharges are a symptom of a wider, systemic problem, and cannot be treated as a stand-alone issue'. It is clear that those system difficulties are the result of often avoidable situations which could be made better by giving people with dementia and their carers more power over their lives, through information and support at and soon after the point of diagnosis. The current review by Audit Scotland of mental health services and the investigation of the Health and Sport Committee of the Scottish Parliament into what happens to people with dementia in Accident and Emergency departments will also offer some interesting and potentially valuable learning.

The aim of the programme

The three pilots will ultimately support the implementation of a Dementia Programme throughout Scotland. Central to the improvement approach is the concept of spreading and adapting existing knowledge to multiple sites to achieve service improvement. The approach makes best use of current thinking on the effective spread of improvement and places a heavy emphasis on integration within the wider local organisation development agenda. It is clear from experiences elsewhere that such an approach does deliver significant service improvements and that success depends greatly on effective project management and excellent facilitation at a local level. The programme will:

- Optimise the overall experience and outcomes of care for people with dementia following on from the point of diagnosis, whatever stage of the illness, and whatever location of the patient
- Maximise the extent to which the person with dementia will begin, from the point of diagnosis, be supported in taking control of their own lives and future plans for their care
- to prevent adverse incidents and avoidable illness including depression and anxiety in people who are diagnosed with dementia and their carers
- Help to co-ordinate dementia services between agencies by placing the person with dementia at the heart of decision making
- Enable teams to develop the skills and confidence to continue to develop services around the person with dementia and help to deliver clinical governance.

¹ *Better Outcomes for Older People*, Scottish Executive ,2005

Approach to be taken in Lothian

The approach, which will be led by the Dementia Services Development Centre involves:

- Developing a set of strategies, principles, ideas and actions for change that local multi-agency teams can use to improve services;
- Sharing these ideas, in conjunction with appropriate change management/improvement methodologies, among participating health and social care staff, along with other independent and voluntary agencies.
- Enabling these teams to adapt and apply the learning to their own real life situation through rapid and intensive change management methods;
- Sharing the learning across all participating sites to help support the broad roll out of good ideas and practice.

Through a formal change process staff will:

- Establish clear care pathways for post diagnostic support as groundwork for the implementation of the NHSQIS implementation of care pathways for dementia
- Improve skills and knowledge of staff caring for people with dementia in techniques of empowerment
- Ensure that all people with dementia have care plans in place to cover all contingencies
- Contribute to improved inter-agency partnerships within localities, particularly between statutory and voluntary sector organisations.

In order to ensure rapid diffusion of good practice it is important to develop the model for Scotland through the pilot phase. The work done in Lothian will be shared with other Health Boards on a regular basis to ensure that a learn and spread approach is adopted.

The pilot will involve a series of training sessions and meetings which will facilitate those teams involved to develop improvement skills and to reach agreement on the measures for the programme. Pilot project teams will take the work forward between these meetings. The Pilot will support the spread of good ideas and innovative ways of working with examples of good practice forming the basis of the programme.

The pilot will involve Primary and Secondary Care, social services, private providers, and voluntary organisations in Lothian and will seek to appropriately involve patients and carers. The team will co-ordinate joint working across all sectors of care to deliver outcomes for people with dementia. The pilot will run for three years.

Key to the success of the pilot is the response of every organisation or agency to be involved in developing the pilot. Evidence from the Forth Valley Project shows that this

may require a lengthy lead in time to the start of the action phase, and to spread the learning taken from the pilot to develop other local teams.

Management

A project manager will be appointed within the host pilot area to work with the team. This person will assist with the administration of the project and ensuring that the processes run smoothly and effectively and that information is shared through different mediums. The project lead will be accountable to Professor June Andrews, Director, Dementia Services Development Centre, the University of Stirling for the purpose of the project. June Andrews has considerable experience of management of improvement programmes within the Scottish health and social care system.

- A steering group will be set up with membership from health, social, voluntary and hopefully independent sector – to include representatives for carers, this will be agreed through discussions with Alex McMahan and Katie McWilliam.
- Key contacts will be identified from each sector at a senior level and they will be contacted in order that views on what needs to be changed, why and what aspirations stakeholders have can be included in the scoping and then project deliverables.
- 1 Project manager, as listed above (Ms J Galbraith) will manage the business processes to allow the project lead to focus on staff development

Performance Management and Accountability

- June Andrews, Director, Dementia Services Development Centre, the University of Stirling, will provide a monthly report to the Scottish Government and to NHS Lothian, and other stakeholders by request, and place the report on the DSDC website and on a website of choice of NHS Lothian.
- Project performance will be measured against the delivery of the programme outcomes.
- The project manager will report on a monthly basis to the steering group. The Steering Group will be chaired by Alex McMahan.
- The project manager will be accountable to Director, Dementia Services Development Centre on a day to day basis.

Forward Programme Capacity to initiate and lead change must be embedded at local level. The process for sharing the learning/experiences from this pilot will be clearly planned at the outset. It is proposed that the Project Manager working with the local teams will be supported locally by existing initiatives within Primary, Secondary and Social care and link closely with members of Local Development Teams both in Health and Social care.

Through this programme based approach we would expect a local pool of expertise to be gathered and to continue to develop to support future change programmes on a whole

system basis. Board level sponsorship will help to ensure that the service improvements delivered locally can be sustained. We would expect to see this reflected in local development plans.

First steps

The collaborative programme and the HEAT target means that there will be:

- People newly diagnosed with dementia who are already in the care home sector or receiving home care
- People who have not been diagnosed who are in the acute health care system, and are cared for by generalist staff in Accident and Emergency/medical/other settings
- People newly diagnosed who have considerable information and support needs that could be served in part by peer group support

In addition the new interest and focus on dementia will mean:

- Pressure on existing dementia related staff
- Increased demand for dementia related education for staff across all systems
- Need for increased awareness.

In the light of this the programme will take first steps in this year to April 2009 by:

- Planning a change event in March 09 which will bring together all interested parties to decide on future action and create the action plan. This event will target up to 200 staff across Lothian and will be held within Lothian. Date to be agreed ASAP. Executive NHS Lothian sponsorship and support will be sought for this event as this will be a key milestone.
- Preparation of briefing for those parties on demographics, policy directions, and current examples of good practice
- Creation of a section on the intranet or the DSDC website (or both) for communication of this information and the monthly reports and records of good practices as they emerge.
- Starting education programmes for care homes where new diagnosis is being made using the care home assistant training programme
- Starting education support for dementia related staff in the NHS by offering places on the Dementia Certificate distance learning programme
- Offering the *manager as leader of dementia practice programme* to a cohort of charge nurses, care home managers, and home care supervisors from February.
- Providing free places on all DSDC programmes currently running for any Lothian based health or social care staff, in addition to the reduced price places for voluntary sector staff
- Offering a free book account for up to £200 of books and other learning materials on the DSDC on line book shop to staff designated by the dementia programme lead.
- All of the above programmes offer a real value to staff across the health and social care systems in Lothian and offer a real opportunity to learn together at different levels but with a clear focus in improving quality and experience of care.

Evaluation

An evaluation of this programme commissioned by DSDC will also be built in, in order to measure the change both in systems but also in culture and behaviours towards this population.

These actions will kick start the programme, but the two years of planned work will be based on the outcomes of the convention in March.

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