



Alzheimer Scotland Facing Dementia Together post diagnostic support pilot

Background

The Scottish Government have funded Alzheimer Scotland and the Dementia Services Development Centre at the University of Stirling to run pilot projects looking at practical solutions for deliverable and effective post-diagnosis support services for people with dementia in three NHS Board areas. One of these pilots is Alzheimer Scotland's Facing Dementia Together project in East Renfrewshire and Renfrewshire, based in our Barrhead office. The project will run until March 2011.

The aim of the three pilots is to support improvement in approaches to post-diagnostic support throughout Scotland, and they will be evaluated and the learning widely disseminated.

The project

Working with East Renfrewshire Community Health & Care Partnership and with Renfrewshire Council and CHP, Alzheimer Scotland's Facing Dementia Together pilot will aim to bring the personalisation agenda into the world of dementia services.

The pilot will aim to support, enable and empower people with early dementia, together with their carers/supporters, to be able to take control of the services they need, now and in the future, and to work with a local authority and health board to develop the systems and approaches to make this a realistic option.

Policy background

Key policy drivers such as Changing Lives¹ and National guidance on self-directed support² highlight the importance of personalisation as a central pillar of the public service reform agenda. Personalisation is recognised as a desirable approach to support services for all care groups. However, although progress has been made in some fields, for example in the support of people with learning disabilities, there is little evidence that people with dementia are being offered the opportunity to benefit from self-directed support. The National Guidance recognises that although all older people are eligible for self-directed support to meet their assessed personal care needs if they are living at home, currently, very few people accessing free personal care do so via self-directed support.

¹ *Changing Lives: report of the 21st century social work review*, Scottish Executive, 2006

² *National guidance on self-directed support*, Scottish Government, 2007

The Changing Lives Service Development Group³ set out the benefits of personalisation as contributing to reducing the need for more costly support packages designed for crisis, devolving more control to individuals and communities and enabling people to become participants rather than simply recipients of support and thus improving the likelihood of achieving success for individuals first time.

In Control, a UK-based project to develop self-directed support, has been at the forefront in England of establishing Individualised Budgets. In Control has been piloting a radically different way of organising social care that fundamentally changes where the power lies and should leave people who use social care services and their families fully in control of their own lives, funding and supports.

One of the barriers to uptake for people with dementia is the widespread lack of post-diagnostic support for people with dementia, which denies them the opportunity to develop their understanding of the illness, enhance their coping skills and improve their chances of being cared for in their own homes for longer. People with dementia need the tools to become active participants in their own health care and to be supported to maintain or recover control in their lives as much as possible at each stage of the illness. It is particularly important that this support should be provided immediately following diagnosis while the person with dementia has the capacity to make decisions and plan ahead.

A second barrier is the lack of local policies, systems and structures to enable care managers to offer people with dementia the opportunity to be made aware of the budget allocated to their care and to control its spending, either through self-directed support (by directly purchasing services or employing personal assistants) or through being made aware of their budget and designing their own support/care plan with the involvement of their carer and care manager.

The aim of this pilot is to extend the level of self-directed support, using methods such as the In Control approach and/or direct payments, to include the care and support of people with dementia, and to empower people with dementia to feel able to take control and make their own choices.

Approach

The pilot will take place in the NHS Greater Glasgow and Clyde area, in East Renfrewshire and Renfrewshire. East Renfrewshire is already developing the In Control approach for other service user groups. Agreement has been reached with the CHCP to commit to developing the approach for a pilot group of people with dementia. Renfrewshire has also committed in principle to the pilot.

Working with Alzheimer Scotland project staff, East Renfrewshire CHCP and Renfrewshire Council Social Work Department will develop self assessment questionnaires and create a Resource Allocation Model for people with dementia, and use these to offer individualised budgets to people with dementia taking part in the pilot. The pilot will be open to people with dementia of all ages.

³ *Personalisation: an agreed understanding*, Changing Lives Service Development Group, 2007

A Post-Diagnostic Practice Manager and a Project Worker have been appointed by Alzheimer Scotland. They will work with newly-diagnosed people with dementia one-to-one and in groups, over a period of up to a year, involving their families and carers as appropriate, to support them to:

- Understand and come to terms with living with dementia
- Benefit from peer support from other people with dementia
- Put in place legal arrangements to maximise their control over future decisions made on their behalf (eg powers of attorney, advance statements)
- Plan ahead for their future needs, discuss options for future care and set out their wishes using advance person-centred planning tools to creatively design services and ‘natural supports’ including support from family, friends and community (recognising that not everyone with dementia will wish to participate).

The Post-Diagnostic Practice Manager will also work with local authority and health staff to:

- Ensure clear links and straightforward referrals to the project for people recently diagnosed with dementia
- Raise awareness of the benefits of individualised budgets for people with dementia
- Assist in facilitating a cultural shift towards personalisation of services for people with dementia
- Ensure that people with dementia who participate in the project are offered appropriate individualised budgets or direct payments and supported to design their own pattern of services.

Outcomes

People with dementia will:

- Be better informed
- Be equipped with skills to manage better the challenges of living with dementia
- Have legal and financial arrangements in place for the future
- Be able to make contact with, and benefit from the support of, other people with dementia
- Be in a position to take control, now and in the future, of services to support them to live at home as independently as possible
- Be supported in the best way for each individual, maximising the benefit from the allocated budget and minimising the need for crisis intervention.

Carers will:

- Be better informed
- Be equipped with skills to manage better the challenges of supporting someone living with dementia
- Be involved in helping the person design the service which will best support them in the future.

Local authority and health staff will:

- Be better informed
- Understand the benefits of and be committed to personalisation for people with dementia
- Be able to inform and support people with dementia and carers in designing creative patterns of services and natural supports which will best support them in the future.

Management

The Post-Diagnostic Practice Manager is line managed by Alzheimer Scotland's Regional Manager Jan Johnston and supported by Kate Fearnley, Alzheimer Scotland's Director of Personalisation.

A reference group will be set up including key contacts from the CHCP and service user and carer representatives.

Forward programme

If successful, the pilot will serve as a model for the roll out of post-diagnostic support services which support the implementation of personalised services for people with dementia throughout their journey of care.

Dissemination of the learning and experiences from the pilot will be planned from the outset, in conjunction with the learning from the other two pilots.