

Dementia care at home

Outline of a research project
funded by the NIHR School
for Social Care Research



Improving the evidence base for
adult social care practice

What are the most effective integrated home care support services for people with dementia and their carers, and how can this be measured?

Support at home for people with dementia and their carers needs to be improved. Government guidance suggests that health and social care should work together to achieve better service provision, but the support received by people with dementia remains of variable quality and effectiveness. Part of the problem is the absence of consensus on what constitutes an optimal integrated care package, and the lack of any measurement tool for assessing service provision in this area.

Support for people with dementia and their carers needs to be sensitive to the care needs and risk factors associated with poor cognition. It is particularly important to work closely with carers and to provide a flexible, responsive, individually-tailored service. To promote more specialist services, a detailed specification is needed of how those services should be provided and what they should achieve, together with a standardised quantitative approach to evaluating the effectiveness and quality of the support.

This project

- will identify the key components of effective and cost-efficient support at home for people with dementia and their carers, and develop a measuring tool to assess dementia services.

It aims to

- review the evidence on what works well, and is economic, when integrated care is provided at home by a range of agencies to people with dementia and their carers
- develop a 'template' of the key component services that are most effective for meeting the needs of this user group
- devise a measuring tool to check how closely the implementation of integrated care service packages measures up against the template
- evaluate the measuring tool through extensive field testing
- disseminate the evidence base and measuring tool to support social care departments in the commissioning and auditing of dementia services.

Research project outline

WHAT IS THE CONTEXT?

England has an ageing population and the number of older people with dementia is projected to increase substantially over the next two decades. In this context, the shift in policy towards providing long-term care at home, whenever possible, rather than in institutional settings makes it crucial to understand the service components that will best enable people with dementia and their carers to live well at home.

Yet very little work has been done in this area to look at the effectiveness of different models of care or to assess service standards. In its 2006 clinical guideline, the National Institute of Health and Clinical Excellence commented that 'the evidence base for recommendations on the planning and organisation for people with dementia and their carers ... [is] small (or non-existent in relation to some services) and generally of a poor quality or not easily applicable to the UK'.

The care and support needs of people with dementia are often complex. Poor insight by the care planners can mean failure to recognise the risks, and the consequent need for support, created by poor cognitive faculties. These challenges can be compounded by pre-existing personality issues and, in some cases, relationship difficulties with family or others. It is also important to recognise that the cultural needs of users and carers, as well as varying cultural attitudes to dementia care, can all have an impact on successfully supporting people with dementia.

Government policy currently advocates that health professionals and social care workers should work together, when appropriate, to provide an integrated approach to care and support. Qualitative studies have shown that multiagency teams can work well, but the variable quality and effectiveness of service provision is still a recurring concern.

The lack of a robust consensus about the evidence base makes it difficult for commissioners to achieve optimal outcomes.

Dementia care at home

Evidence confirms the need to work especially closely with carers, and to provide a flexible, individually-tailored packages of support. Other specific issues for dementia care include:

- vulnerability to abuse
- inability (due to cognitive incapacity) of service users to take decisions about their care
- behavioural difficulties associated with the disease
- dealing with the expected progression of the condition.

Practitioners would benefit greatly from robust information about what constitutes a good, effective, and cost-efficient, integrated package of services and how it should work in practice. Just as important is a transparent methodology for measuring what services do and how they work, so that a package of services can be judged according to the success it achieves. Evaluation that is both comprehensive and quantitative is needed in order to drive improvement and quality in integrated care.

While there is some overlap with 'generic' service approaches, good dementia care at home requires some specific features. The Department of Health's 2009 National Dementia Strategy called for more specialist services. Here, too, there is a need for a detailed specification of how these specialist inputs should be provided.

This project will establish the overall evidence base for what works well, and will provide practical tools for social and health care commissioners, service providers and other professionals working to support people with dementia and their carers to continue to live well at home.

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HOW WILL THE PROJECT WORK?

An Expert Advisory Group will be set up to provide input throughout the study, to ensure that discussions are grounded in the realities for users and services providers. Members will include people with dementia, carers, voluntary organisations, commissioners, practitioners, service managers and researchers.

STAGE 1: Establishing a consensus

Following a review of the literature and current practice guidance, the research team will identify the proposed criteria for good quality, effective, and cost-effective dementia care at home. The draft criteria will be refined through an iterative process with stakeholders and experts in order to reach a consensus on the criteria that typify high quality care.

STAGE 2: Developing a service template

Phase I: A national survey of perceived good practice in dementia care at home.

Respondents will be asked what could/should, be covered by the project's new measurement tool, and to identify any existing audit tools. The survey will be sent to a sample of Adult Social Care Services, plus service users and carers who will be approached via the Alzheimer's Society and Age Concern. Issues relating to charges, individualised budgets and self-funding will be part of the survey.

Phase II: Production of a 'template' for high quality service, based on the Stage 1 work and survey results. Cost implications will be considered. The service specification will be detailed, addressing issues such as: how many staff are needed per service user; staff training and grade; 'key worker' practises; referral and working practices; links with other services; service objectives; management and leadership; responsiveness, flexibility, and continuity; and the bespoke individual nature of the service.

STAGE 3: Deriving a measurement tool

A measurement tool based on the domains used in the service template will be devised through an iterative process with Expert Advisory Group input.

The focus will be on producing a practical measurement tool with clear operational definitions of the service elements necessary for good quality dementia care at home. It will provide a standardised way of evaluating how closely services match the agreed template – a 'fidelity index' for assessing how faithfully and fully the framework has been pursued. It will be applicable throughout England.

As no one service model is likely to be perfect, the 'fidelity index' will reflect a range of service elements. The tool can then show where services have areas of 'good' achievement while also indicating where improvements would be worthwhile. It is likely that officially recorded figures, or returns from service records, will be required to be entered in parts of the final version of the index.

Significant discussion and iteration of the tool will be needed to ensure its acceptability, clarity, ease of understanding and validity. The project team will pilot the emerging tool with Adult Social Care Services team leaders, managers, commissioners, and providers as well as service users and carers associated with the Expert Advisory Group. The tool will be finalised in the light of the feedback.

STAGE 4: Formal field testing

Extensive field testing will be carried out to test the utility, acceptability, consistency, reliability and validity of the measurement tool ('fidelity' index) and to explore further the validity of the service quality criteria developed in Stage 1. The field testing will take place with at least 30 provider teams in the Trent area, offering different service and demographic settings.

Project publications

The project's main output will be a resource (planned to be web-based) to enable comparison via a benchmarking system. Health and care services can compare their results to (anonymised) summary findings from others who have submitted data. The project's findings will be disseminated and publicised through the Expert Advisory Group channels, conference presentations, articles in peer reviewed journals and service-orientated publications.

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HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

This project will establish the evidence-based critical components of good dementia care at home, and thereby develop a tool to assess services against an agreed quality template (a service 'fidelity index'). The project outputs are particularly relevant for service commissioners as it will better equip them to ensure that arrangements are put in place to achieve optimal social care outcomes for people with dementia and their carers. The service template will guide commissioners and providers to an understanding of the key component elements in a good quality care package, so that health and social care resources can best be deployed in an integrated way to support individuals to live well at home. The use of the measurement tool will provide a standardised assessment for professionals with the responsibility for auditing dementia services, which will have a positive impact on service improvement. Improved care and support at home should help to reduce the development or exacerbation of the circumstances that might lead to an individual with dementia needing institutional care.

The NIHR School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research to develop and improve the evidence base for adult social care practice in England. It officially launched on 1 May 2009 with funding of £15 million over five years.

The School conducts and commissions high-quality research across five overlapping programme areas:

Prevention and reduction – How can we best prevent or reduce the development or exacerbation of the circumstances that lead to the need for social care?

Empowerment and safeguarding – How can we best empower and safeguard people who use social care services?

Care and work – How can we best equip and support people – practitioners, volunteers, informal carers – to provide optimum social care? How can we ensure that people who use social care and their carers are enabled and supported in paid work and other types of meaningful activity?

Service interventions, commissioning and change – What interventions, commissioning and delivery arrangements best achieve social care outcomes?

Resources and interfaces – How can social care and other public resources best be deployed and combined to achieve social care outcomes?

Further information about the NIHR School for Social Care Research is available at www.sscr.nihr.ac.uk

Project title:
Improving effective integrated home support for people with dementia and their carers: development of a service fidelity index

Timescale:
July 2010
to December 2012

Budget:
£244,298

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