

Dementia Working Group

Terms of Reference

Introduction

The increase in the numbers of older people in our population is well documented. Across the UK those aged over 65 years are predicted to rise from 16% of the population in 2004 to 21% by 2024. The number of people aged over 85 will nearly double within the same time period to almost two million. This development in the demographic structure of our society brings a wide set of challenges for policy and practice in health and social care.

In an increasingly ageing population the numbers of people with dementia in the UK is very marked:

Estimated numbers of people with dementia in the UK	
2006	775,200
2010	870,000
2050	1,700,000

Source: Alzheimer's Society

We know that the incidence of dementia increases with age; one in fifty people over 65 years have dementia and for people over 80 years, the incidence rises to one in five.

New research suggests that over half of all people with dementia in the UK are resident in care homes. By 2039, nearly three quarters of a million care home places will be needed to satisfy demand which is almost certainly unsustainable. Further exploration is required of models of good quality, affordable domiciliary care for people with dementia.

From the Gold Standards Framework, typically a GP will have twenty deaths a year; seven will be due to dementia, frailty and decline. The trajectory of the disease is less predictable than for other life threatening conditions and people living with dementia may experience a prolonged period of decline which can be very challenging for their carers and for professional staff. Symptom control can be particularly difficult, not least because of cognitive impairment and communication issues.

Carers of people with dementia experience greater strain, distress and higher levels of psychological morbidity than carers of other older people.

Co-morbidity is a significant feature of dementia in what can be a complex interaction of illnesses. More people are living with a number of chronic illnesses which, together, present a range of difficult problems for health and social care professionals. The individual may receive care and support from a wide range of professionals and others – coordination of this support is key and is a challenge in working across professional groups, organisational boundaries and different philosophies of care. Specifically for people with dementia, this can become more fragmented whereby certain professionals care for the 'physical' needs, others the 'mental health' needs. Dementia must also be considered a significant co-morbidity in its own right for all other conditions. Approximately 29% of people aged over 85 years with cancer, circulatory disease and respiratory disease have dementia as a co-morbidity.

It is against this background of an ageing population facing the challenges of caring for an increasing number of people living and dying with dementia that a series of publications are emerging. This includes NICE/SCIE guidance for health and social care professionals working with people with dementia and their carers published in 2004, CSCI's State of Social Care Report published in 2005/06 and 'Dementia UK', the recent Alzheimer's Society report. The National Audit Office publication on health and social care available to people with dementia and their carers is due in June 2007 and the Department of Health has a forthcoming strategy for end of life care. In addition, a range of assessment tools has been developed or is being adapted for dementia care.

Background

The National Council for Palliative Care's mission is to ensure that all those who need palliative care have access to appropriate services regardless of diagnosis. NCPC's Older People's Policy Group has concentrated on this remit. NCPC's emerging work has focused on the palliative care needs of people with dementia with the recent publication 'Exploring Palliative Care for People with Dementia', followed by two highly successful workshops in October 2006 and January 2007.

In recognition of this work and the need for its extension, NCPC has recently been awarded funding by Lloyds TSB Foundations for a project to promote increased and better quality palliative care for people living with dementia.

Objectives

The aim of this project is to:

- map current provision of palliative care services for people with dementia
- highlight gaps in provision within different care settings
- understand user and carers' needs of palliative care services, including marginalised and diverse groups
- identify and share notable practice
- develop practical guidance to promote palliative care for people with dementia.

Monitoring and evaluation will be an integral part of this project and will take place within the established structure for review within the policy unit at NCPC. The project will be included in the NCPC's formal process of external evaluation by King's College London. In addition, specific measures will be deployed to assess the impact of the dementia project. This will include:

- publication sales
- conference/events attendance
- dissemination of guidance
- invitations to contribute to external conferences, seminars etc.
- press coverage
- raised levels of user/carer awareness.

There will be wide dissemination of the findings from this project using NCPC's national and local structure.

Approach

NCPC's Older People's Policy Group approved the formation of a Dementia Working Group (DWG) to steer the overall direction of this project and provide expert guidance.

The DWG will meet quarterly. These terms of reference have been prepared for the first meeting of the DWG which is scheduled for 23 February 2007. Members are:

Sharon Blackburn, Executive Director – Older People, Heart of England Housing and Care Ltd

Mary Casey, Joint Professional Advisor Palliative Care, Healthcare Commission/CSCI

Rachael Dutton, Research Manager, Dementia Voice and Housing 21
Clive Evers, Director of Information and Education, Alzheimer's Society,
Barbara Stephens, Chief Executive, For Dementia
Dr Victor Pace, Consultant in Palliative Medicine, St Christopher's Hospice
Lucy Sutton, National Policy Lead, NCPC
Alison Blight, Dementia Services Project Manager, NCPC

Rachael Takens-Milne from Lloyds TSB Foundations will attend meetings as an observer in her capacity as a representative of the funding organisation.

In addition, the project is co-opting a wider reference group to ensure access to specialised advice. Members could include:

Dr Gillie Evans, GP, Jenner Practice, Peterborough
Maria Parsons, Executive Director, London Centre for Dementia Care
Dr Claud Regnard, Consultant in Palliative Care Medicine, St Oswald's Hospice, Newcastle upon Tyne
Dr Julian Hughes, Old Age Psychiatrist, Institute for Ageing and Health, University of Newcastle
Professor Murna Downs, Chair in Dementia Studies, University of Bradford and Head of Bradford Dementia Group
Dr Graham Stokes, Consultant Clinical Psychologist, South Staffordshire Healthcare NHS Trust and Head of Mental Health, BUPA Care Services
Dr Duncan Forsyth, Chair, British Geriatrics Society
Dr Liz Sampson, MRC Research Fellow, Royal Free and Univesity College Medical School.

This project will be highly collaborative; we will work closely with other national bodies who have expertise and knowledge in the area.

We will use a range of methods to address our objectives. This could include all or a combination of the following:

- documentation review
- structured interviews
- survey of user and carer requirements
- notable practice visits.

Finally it is important to note in this terms of reference that although this project sits within the overall remit of the Older People's Policy Group, the findings and learning which will be developed will apply to all people with dementia irrespective of age.

Resources, reporting arrangements and timescale

Funding for this project allows two days a week of project management time. The project will be completed by February 2009.

There will be flexibility in the organisation and timing of reporting arrangements. The key outputs with reporting dates are as follows:

Briefing bulletin To include mapping of current provision and gaps	end Jun 2007
Focus on dementia To include reporting of user/carer needs	end Jan 2008
NCPC event – developing palliative care for people with dementia	Jan/Feb 2008
Final report	end 2008
Final Event – meeting the palliative care needs of people with dementia	Jan/Feb 2009
Communications planning To disseminate findings/learning to external audiences Including a combination of: press liaison; updates in NCPC's <i>Information Exchange</i> ; <i>E-News</i> and <i>the website</i> ; area and country events; national conferences etc.	on-going

Alison Blight
National Council for Palliative Care
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