

How can people with dementia be assisted to maintain independence and quality of life?

The number of people with dementia is set to escalate due to a combination of population ageing and increased longevity. It is therefore important to design services capable of meeting future need and the current focus on increasing numbers provides an ideal stimulus for change. Part of this switch should be a more positive emphasis on promoting quality of life and well-being.

What is dementia?

The term 'dementia' describes a group of conditions that are all characterised by significant, irreversible cognitive decline over time. They include Alzheimer's disease, vascular dementia, lewy body dementia and frontal lobe dementia. There are also a number of other, less common conditions (each with their own specific signs and symptoms) which also result in dementia (Stephan and Brayne, 2008).

The effect of the dementia upon a person can be *mild*, *moderate* or *severe*; only around one third of people with a diagnosis of dementia are at the severe end of the scale, requiring constant supervision. Also, some people will decline rapidly whereas in others the symptoms become apparent over a longer period of time.

According to carers, the most commonly recognised initial signs of dementia are poor memory, confusion and disorientation (in time, in place and in person in the advanced stages of the disease). At all stages of the illness, the disabling effects of impaired memory can be catastrophic. Living with a situation where one's memory is so poor that a lifetime of established habits and routines cannot be recalled, where the names of friends and relatives are forgotten, and where familiar places and situations become unfamiliar is extremely distressing. Perceptual disturbance is a further common symptom in the later stages, often overlooked.

Even though dementia can occur at any age, it is most prevalent in older people, and particularly those in advanced old age, with 20 per cent of those aged 80 years and over having some form of dementing illness. The age profile of people who are likely to develop the condition means that a whole range of other, unmet needs associated with the ageing process can co-exist (Xie et al, 2008).

Recent policy and legislation

There has been recent acknowledgement of the neglect of dementia within health and social care policy; for example it was not satisfactorily addressed within any of the National Service Frameworks (National Audit Office, 2007). The introduction of evidence based guidelines for dementia (NICE and SCIE, 2006) was significant and is now being followed by a National Dementia Strategy, to be published by early 2009.

Implementation of the interim findings of the National Strategy is already being taken forward by the Care Standards Improvement Agency (CSIP). The implementation of the Mental Capacity Act (2005) in 2007 is also impacting significantly upon established

understanding of how services for people with dementia should be provided. The Act states that an individual has capacity to make decisions about their treatment and care unless it can be demonstrated that this is not the case. Independent Mental Capacity Advocates (IMCAs) can be involved to represent the person with cognitive impairment.

Changing health and social care practice

Pharmacological interventions are now available which can alleviate the symptoms of dementia in the mild to moderate stages. This has led to new hope and a growing realisation that people with dementia can also benefit from different forms of intervention that were previously denied to them. The previous understanding that people with dementia cannot learn new skills and therefore any intervention is at best going to fail and at worst going to have an adverse effect upon all involved is being replaced. The benefits of working with the strengths and abilities of the person with dementia alongside those of their carer is slowly being recognised, whereas previously services were focussed almost exclusively upon supporting the carer. This significant shift in philosophy is described within UK guidelines for supporting people with dementia and their carers (NICE and SCIE, 2006).

Best practice in dementia care now includes a range of interventions to stimulate and support preserved abilities and self management in the earlier stages of the condition. There is an emphasis on promoting quality of life and maximising the functioning of the person and their carer at all stages of the disease process (Vernooij-Dassen and Moniz-Cook 2005; Graff et al, 2006; Mountain, 2006). It is also recognised that interventions must take into account all aspects of the health and wellbeing of the person with dementia and their carer: mental, physical and spiritual. The value of new technologies to assist the person with dementia and their carer is a further important dimension, which is helping to promote a new vision for dementia services. The range of interventions which fall within the rubric of best practice now include the following:

- early disclosure of the diagnosis and support with the consequences of disclosure
- a focus on the needs of the person with dementia
- interventions that might facilitate self management
- meeting needs for professional education and support
- a whole systems approach towards treatment and care

Early diagnosis and support with the consequences of disclosure

Early diagnosis is essential, as it is only following disclosure that the person and their carer can begin to come to terms with the implications of diagnosis and be helped to identify the support and assistance they require and plan for the future (Fortinsky, 2008). Individual concerns following diagnosis frequently include future incontinence, cognitive and functional decline and the impact of the condition upon family members. There is also a desire to continue with social and leisure activities for as long as possible (Moniz-Cook et al, 2006). Practitioners must be willing to disclose the condition to the person as early as possible and then assist them to take informed decisions about their treatment and care, alongside their carer (Vernooij-Dassen and Olde Rikkert 2004; Moniz-Cook 2008). The proactive involvement of significant carers should commence from the outset.

A focus upon the needs of the person with dementia alongside their carer

The commonly held view that people with dementia cannot learn new skills and therefore any intervention is at best going to fail and at worst going to have an adverse effect upon the person and their carer is being challenged. The UK Alzheimer's Society's *Living with Dementia Programme* is one example of an alternative model whereby

individuals are helped to continue to live a quality life despite the illness. Concepts of self management for dementia are now beginning to emerge which centre upon the person with dementia alongside their carers (Vernooij-Dassen and Olde Rikkert 2004; Vernooij-Dassen and Moniz-Cook 2005; Mountain, 2006). This approach recognises that people in the early to middle stages of the illness are able to maintain self efficacy and independence, and can derive benefit from education about their condition and how to manage it. There is also a renewed emphasis upon the value of rehabilitation for people with dementia (Mountain and Moniz-Cook, 2007). The Expert Patient Programme has been at the forefront of implementation of self management for people with long term conditions in the UK (DoH, 2001) and is now working with Sheffield Hallam University on production of a programme for people with dementia. Within this approach, family carers will be offered education to equip them to enable the person they support as well as identifying methods of helping them to continue to care. Services therefore need to change to a model of enabling carers to cope with the demands of their caring role.

Interventions that might facilitate self management

Any self management approach for people with dementia must adopt a realistic stance and not imply a lifestyle or skill level to them or to their carers that may be unattainable or unsustainable. Nevertheless self management offers many possibilities which, as yet, have not been widely provided to people with dementia. Domains which might be included within a tailored programme of self management include encouraging personal coping resources; identifying activities to help maintain memory, social engagement and pleasure; strategies to assist with memory and daily living; information on maintenance of physical health and well-being (including managing medicines and co-morbid physical health conditions); information about how to access and use available support; managing new challenges; education to equip family carers to enable the person they support to do as much they feel able to; and accessing social support for the person and their relatives. It should also provide practitioners with advice on how to manage disclosure of diagnosis so that optimal decisions about treatment and care can be agreed by patients and by their relatives (Moniz-Cook, 2008).

Some of the interventions described above are not new but to date have not been considered to be important for people with dementia, for example

- *The value of maintaining physical health and wellbeing:* Heyn et al (2004) found that exercise led to significant improvements in health related physical fitness and also to improvements in cognitive, functional and behavioural outcomes in people with dementia.
- *Enabling access to rehabilitation:* There is no reasonable rationale for refusing access to rehabilitation as demonstrated by the studies of Huusko et al (2000) and Rydholm Hedman and Grafstrom (2001). It is now accepted that people with dementia should be provided with rehabilitation and intermediate care services if they might potentially benefit, with this being reinforced within the forthcoming National Dementia Strategy.

Other interventions described as falling within the rubric of self management have been provided over time but there now needs to be a re-appraisal of how they are delivered and when, for example:

- *Community based occupational therapy:* Graaf et al (2006) demonstrated improvements in functional ability of people with mild to moderate dementia and reduced burden on caregivers following a five week programme of occupational therapy which was tailored to meet the holistic needs of the individual and their carer.
- *Enabling participation and enjoyment:* An examination of the extent of disability

experienced by people with dementia using the International Classification of Functioning, Disability and Health framework (ICF) found that hobbies and interests were compromised early on in the disease process (Muò et al, 2005). Meeting individual needs and aspirations should be a focus at all stages of the illness. However, traditionally, recreational activities have been used for moderate to late stage dementia management, provided within settings such as day provision.

- *Use of technology to promote enablement:* In common with other people with disabilities, people with dementia can benefit from compensatory technologies such as simple environmental adaptations and equipment to facilitate mobility and independence as well as use of sophisticated technologies (Marshall, 2004). Technological devices that are currently becoming more commonly available (recently promoted through the DH Telecare initiative) include use of sensors to detect movement and the resident's use of various items in the home, community alarm systems for help and reassurance and devices to promote the safe undertaking of activities of daily living. Gadgets are also available to prompt memory and recall. Researchers have also been exploring the use of body-worn sensors and mobile phone technology to track movement outside the home while at the same time allowing people to go out independently (Miskelly, 2005; Robinson, 2007). The potential benefits that technologies can provide to people with dementia and their carers will continue to be exploited and several comprehensive reports are available detailing progress made with developments and the various ethical and service considerations inherent in their use (Jones, 2004; Cash, 2004).

Meeting needs for professional education and support

The need for improved professional education in dementia treatment and care so that staff can be provided with the necessary tools and support to change the ways that services are delivered is self evident. Necessary changes to professional practice include, but are not restricted, to the following:

- providing early diagnosis and subsequent management of disclosure
- delivering tailored programmes of interventions which meet the range of needs (both individual and combined) of the user and their carer
- ensuring regular re-assessment and alterations to the intervention plan in line with changing needs
- maximising upon what new technologies can offer.

Successful delivery of all of the above requires on-going education and mentorship (Keady et al, 2004; Iliffe and Wilcock, 2005).

Redesigning services within a whole systems approach

To maximise the effectiveness of interventions provided through individual services, they must be drawn together into a coherent pattern or *whole system* so that users are easily able to move from one element of the system to another as their needs change over time (Audit Commission, 2002). The system must contain elements that are able to meet the needs of people with dementia and their carers at different stages of the illness with appropriate needs assessment procedures. To ensure that people can benefit to best effect, services have to work together, referring people on to the most appropriate settings in a timely and seamless manner as their needs change over time, including access to medical rehabilitation if the person's health needs require it. Successful implementation

of the whole system demands a heightened awareness of the goals of other forms of provision within the locality on the part of staff in all services and the ability to recognise when other services are necessary. This will require the development of specific skills on the part of all those engaged in service delivery, particularly those required to conduct sensitive, user centred assessments with people with dementia and their carers (Mountain, 2008). A number of services will require re-designing to take into account different patient pathways and the increasing use of new technologies.

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Resources (all accessed October 2008)

Alzheimer's Society: www.alzheimers.org.uk

Care Standards Improvement Agency (CSIP): Implementation of the National Dementia Strategy <http://www.olderpeoplesmentalhealth.csip.org.uk/everybodys-business.html>

Care Standards Improvement Agency (CSIP): The Telecare LIN

<http://networks.csip.org.uk/IndependentLivingChoices/telecare/>

Summary of the Mental Capacity Act:

http://www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/theweek/Chiefexecutivebulletin/DH_4108436

References

Audit Commission (2002) *Integrated services for older people: building a whole system approach in England*, London: Audit Commission

Cash M (2004) *At home with assistive technology*, Bristol: Dementia Voice

Department of Health (2001) *The expert patient: a new approach to chronic disease management for the 21st century*, London: Department of Health

Fortinsky RH (2008) Diagnosis and early support, in M Downs and B Bowers (eds) *Excellence in dementia care*, Abingdon: Open University Press

Graff MJL, Vernooij-Dassen MJM, Thijssen M, et al (2006) Community based occupational therapy for patients with dementia and their caregivers: randomised controlled trial, *British Medical Journal*, 333, 1196

Heyn P, Abreu BC, and Ottenbacher KJ (2004) The effects of exercise training on elderly persons with cognitive impairment and dementia: a meta-analysis, *Archives of Physical Medicine and Rehabilitation*, 10; 85 (10), 1694-1704

Huusko TM, Karppi P, Avikainen V et al (2000) Randomised, clinically controlled trial of intensive geriatric rehabilitation in patients with hip fracture: subgroup analysis of patients with dementia, *British Medical Journal*, 321, 1107-1111

Illiffe S and Wilcock J (2005) The identification of barriers to the recognition of, and response to, dementia in primary care using a modified focus group approach, *Dementia*, 4, 73-85

Jones K (2004) *Enabling Technologies for People with Dementia*, www.enableproject.org

Keady J, Woods B, Hahn S et al (2004) Community mental health nursing and early intervention in dementia: developing practice through a single case history, *International Journal of Older People Nursing* in association with *Journal of Clinical Nursing*, 13, 6b, 57-67

Marshall M (2004) Rehabilitation: environmental aids and adaptations, in M Marshall (ed) *Perspectives on rehabilitation and dementia*, London: Jessica Kingsley

Miskelly F (2005) Electronic tagging of patients with dementia and wandering using mobile phone technology, *Age and Ageing*, 34, 497-499

- Mountain G (2006) Self management and Dementia: an exploration of concepts and evidence, *Dementia*, 5, 429 - 447
- Mountain G (2008) Assessment and dementia, in M Downs and B Bowers (eds) *Excellence in Dementia Care*, Abingdon: Open University Press
- Mountain G and Moniz-Cook ED (2007) Rehabilitation for people with dementia: further development of an evidence based framework, *Les Cahiers de la Fondation Médéric Alzheimer*, 3, 5-66
- Moniz-Cook ED (2008) Assessment and Psychosocial Intervention for older people with suspected dementia: a Memory Clinic perspective, in K Laidlaw and B Knight (eds) *Handbook of Emotional Disorders in Late Life Assessment and Treatment*, Oxford: Oxford University Press
- Moniz-Cook E, De Lepeleire J and Vernooij-Dassen M (2004) Chronic disease management – What can be learned from dementia management? *British Medical Journal*, 328, 99 (7453) 1396 -d
- Moniz-Cook E and Vernooij-Dassen M (2006) Timely psychosocial intervention in dementia: a primary care perspective, *Dementia*, 5, 307-315
- Moniz-Cook E, Manthorpe J, Carr I et al (2006) Facing the future: a qualitative study of older people referred to a memory clinic prior to assessment and diagnosis, *Dementia*, 5, 375-395
- Muò R, Schindler A, Vernerio I et al (2005) Alzheimer's disease associated disability: an ICF approach, *Disability and Rehabilitation*, 27, 1405-1413
- National Audit Office (2007) *Improving Services and Support for People with Dementia*, London: Audit Office
- National Institute for Clinical Excellence and Social Care Institute for Excellence (2006) *Dementia: supporting people with dementia and their carers in health and social care*, London: NICE and SCIE
- Robinson L, Hutchings D, Corner L et al (2007) *Health Technology Assessment*, 10(26), 1-124
- Rydhholm Hedman A-M and Grafstrom M (2001) Conditions for rehabilitation of older patients with dementia and hip fracture – the perspective of their next of kin, *Scandinavian Journal of Caring Services*, 15, 151-158
- Stephan B and Brayne C (2008) Prevalence and projections of dementia, in M Downs and B Bowers (eds) *Excellence in dementia care*, Abingdon: Open University Press
- Vernooij-Dassen M and Olde Rikkert MGM (2004) Personal disease management in dementia care, *International Journal of Geriatric Psychiatry*, 19, 715-717
- Vernooij-Dassen M and Moniz-Cook ED (2005) How can the quality of home based interventions be improved? *Dementia*, 4, 163-169
- Vernooij-Dassen M, Derksen E, Scheltens P et al (2006) Receiving a diagnosis of Dementia: the experience over time, *Dementia*, 5, 397-410
- Xie J, Brayne C, Matthew FE et al (2008) Survival times and people with dementia-analysis from a population based cohort study with 14 year follow up, *British Medical Journal*, 336, 258-265

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