

Ten questions to ask if you are scrutinising...

...services for people with
dementia





The Centre for Public Scrutiny

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This guide is one of a series by CfPS designed to help overview and scrutiny committees (OSCs) carry out their scrutiny work on health, social care and related topics. It is intended for OSCs that wish to take a broad overview of how well their local authority and its partners are supporting people with dementia and those who care for them. It identifies ten question areas, all of which need to be addressed if local areas are to provide an effective response.

For OSCs that wish to carry out in-depth reviews of any of the topics covered in this guide, other [CfPS titles of particular relevance](#) include: *A good place to grow older: practice guide for overview and scrutiny committees* and its companion, *A good place to grow older: ten questions to ask if you are scrutinising local preparation for the ageing society*; *Transforming adult social care*; *Adult Safeguarding*; *End of life care* and *Walk a mile in my shoes – scrutiny of dignity and respect for individuals in health and social care services*.



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The extent and impact of dementia

The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of how people's brains function and how, consequently, their minds and bodies work. Alzheimer's Disease is the most common form of dementia. Alzheimer's Disease International calls dementia "the single most significant health and social crisis of the 21st century" (ADI 2010). There are estimated to be over 750,000 people in the UK with dementia and numbers are expected to double in the next thirty years, estimated to cost £20bn a year to the economy. One in 14 people over 65 years of age and one in six people over 80 has a form of dementia – from these figures, OSCs can work out how many people with dementia are likely to be in their population (Alzheimer's Society updated January 2010).

Although dementia is primarily a condition associated with older people, there are also a significant number of people (currently around 15,000 in the UK) who develop dementia earlier in life. Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn annually. Up to one in four hospital beds at any one time is occupied by a person over the age of 65 who has dementia (Alzheimer's Society 2009). Such people stay longer in hospital than others: the excess cost is estimated to be £6m annually in the average General Hospital. (DH September 2010).

Despite the increasing numbers of people with dementia and the huge impact it has on them, on their families and on health and social care services and budgets, as a society, we are not doing as well as we could to support people with dementia and those who care for them. Two thirds of people with dementia never receive a diagnosis. The UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia. Only a third of GPs feel they have adequate training in diagnosis of dementia. Two thirds of people in care homes have dementia. Over half are poorly occupied. Behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs (an estimated 180,000 people currently). In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of their prescription (DH September 2010, Banerjee, 2009).

The proportion of older people from ethnic minority groups in the UK is small, but increasing steadily as this section of the population ages. It is therefore predicted that the number of people with dementia from BME groups will rise quickly. However, many services for people with dementia from these communities remain inappropriate and

inaccessible.

People with learning disabilities may experience a higher risk of dementia because of premature ageing. Also, people with Down's syndrome have an increased genetic risk of developing dementia. Additional specialist support and services need to be provided to meet their increasing needs (Alzheimer's Society, updated January 2010).

National strategy and local implementation

Although there has been concern for some years about the extent and impact of dementia, a comprehensive national response was slow to develop, with the first National Dementia Strategy (NDS) published in January 2009. The strategy identified 17 objectives for improvement including awareness-raising, early diagnosis and intervention, information, support for people with dementia and their carers, peer support, hospital services, intermediate care, housing, care homes, end of life care and research. The objectives also addressed implementation, including joint commissioning, national and regional support, regulation, and workforce development. The strategy was supported by funding of £150 million over two years until 2010-11 and 40 demonstrator sites were chosen to pilot dementia advisors and models of peer support.

The strategy was widely welcomed but implementation is regarded as problematic. An inquiry by the All-Party Parliamentary Group on Dementia found that half of PCTs had missed the deadline to produce joint plans with councils to implement the strategy and two-thirds could not account for how the funding had been spent (2010). The National Audit Office highlighted uneven progress across the country and noted that dementia was not a national priority for PCTs, leading to insufficient attention in some areas (2010). Other significant concerns include insufficient investment in dementia research and inappropriate use of antipsychotic medication resulting in suffering and untimely deaths.

In *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy* (DH September 2010) the coalition government updated the previous dementia implementation plan, setting out four national priority objectives:

- ◇ improved early diagnosis and intervention
- ◇ improved quality of care in general hospitals
- ◇ living well with dementia in care homes
- ◇ reduced use of antipsychotic medication.

The implementation plan is not intended to be prescriptive – the



government notes that the pace of change will vary dependent on local circumstances. However, NHS commissioners and their partners will be required to publish information on progress.

National cross-sector commitment to improving dementia support is demonstrated through the Dementia Action Alliance led by the Alzheimer's Society. Over forty major organisations including the Department of Health, the Local Government Group (LGG), and the Care Quality Commission have signed a National Dementia Declaration committing them to improving outcomes identified by people with dementia and their carers (Dementia Action Alliance 2010). Each organisation has produced an action plan and will report on progress. For example, one action by the LGG is to develop briefings for lead members and provide opportunities for discussion at regional lead member networks.

Dementia has been included as one of the commitments in the NHS Operating Frameworks for 2010/11 and 2011/12 (DH June and December 2010a). The latest framework indicates that people with dementia and carers need information to understand the range and quality of local services and confirms that NHS organisations are expected to make progress on the NDS including the four priority areas identified in the new implementation plan. It also states that NHS organisations should agree with social care commissioning partners what aspects of the strategy could be delivered using partnership arrangements under section 75 of the NHS Act 2006.



In the wider context, measures in the Health and Social Care Bill, at time of writing passing through Parliament, will be fundamental for the future support for people with dementia and their carers (HM Government 2011). The pace and scale of reform is causing widespread concern to those with an interest in health and care, within the area of long-term conditions, where people have complex needs and require coordinated health and social care support, seen as particularly problematic. Under the new arrangements GP consortia will not necessarily be coterminous with local authorities leading, initially at least, to more complex local planning, commissioning and delivery arrangements. More fundamentally, competition for NHS services will be promoted, and a variety of different providers responsible for particular sections of the health and care journey may well prove more difficult to co-ordinate.

Health and wellbeing boards will have the role of co-ordinating local commissioning and promoting integrated approaches. Led by local authorities, GP consortia will be statutory members of the boards and must jointly produce joint strategic needs assessments and health and



wellbeing strategies. It is essential that GP consortia identify dementia as a key local priority and that health and wellbeing boards ensure that it is approached in an integrated way. The health scrutiny function of local authorities working with local HealthWatch will be vital for oversight of these matters. Increased health scrutiny powers in relation to providers of NHS-funded services and individuals, such as directors of foundation trusts, will be helpful in this work.

Good practice, quality and standards – useful information for OSCs

Information to support national and local delivery on the NDS, including good practice and guidance on the 17 objectives, is compiled on the National Dementia Strategy Information Portal. The portal forms a comprehensive resource for OSCs seeking further information for a dementia scrutiny review.

The Social Care Institute for Excellence (SCIE) dementia gateway also provides information on good practice covering areas such as keeping active, decision making and managing difficult situations.

The government has commissioned a national audit of dementia services to establish the level of performance in areas such as memory services, reducing anti-psychotic medicine, senior clinical leads in hospitals, and expenditure on dementia services. The report, from the Information Centre for Health and Social Care was expected by the end of 2010; at the time of writing its final report has not yet been published.

In its updated Implementation Plan, the DH indicates that it is working with partners to develop key outcomes which people with dementia and their carers can expect from services. It sets out an initial nine quality outcome statements, identified as important by people with dementia, with associated descriptors for example;

'I was diagnosed early' – People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.

The DH indicates that local areas may find this approach helpful for planning. The initial quality outcomes are included as headings to the ten question areas in this guide.



A suite of standards for dementia has also been produced by the National Institute for Health and Clinical Excellence e.g. *people with suspected dementia are referred to a specialist memory assessment service* (NICE 2010). The standards show what high-quality health and social care for people with dementia should look like. They are to be used by the NHS Commissioning Board, GP commissioning consortia and health and care providers to deliver outcomes in the NHS Outcomes Framework (DH December 2010b). Dementia standards are identified as particularly relevant to Domain Two *Enhancing quality of life for people with long-term conditions*. Dementia quality standards are referenced throughout the ten questions in this guide. (At the time of writing the Social Care Outcomes Framework has not been published.) A joint guide to dementia by NICE and SCIE from 2006 is also still operational.

The financial context

The NDS was published at a time of financial crisis and is being implemented in conditions of severe economic constraint. The intention of the previous government was that the strategy should be implemented largely through efficiency savings. The National Audit Office indicated that the DH did not have evidence on current and future costs and benefits and that the strategy was likely to cost much more than the estimated £1.9 billion over ten years (2010). It also stated that joined-up, well-informed commissioning, and releasing or re-directing resources from secondary to primary care and from the NHS to social care were essential to its effectiveness – but would prove difficult in the financial climate.

The coalition government indicates that the DH must deliver more efficiently and effectively using the resources available and must support the NHS and social care to do the same. It states that £8.2 billion is already spent on dementia and within this there is potential for savings to be identified and reallocated to new dementia services.

The Role of OSCs in scrutinising dementia services

The economic and social impact and extent of dementia means that it is an excellent topic for OSC review. This is compounded by the fact that the national strategy has had a slow and patchy start. A number of OSCs have considered aspects of dementia services. Some examples are briefly described below:

Manchester Health and Wellbeing OSC has looked at progress on the Manchester Dementia Strategy, how it fits within the Joint

Commissioning Executive for Mental Health and how it sits within the context of recent governmental changes:

http://www.manchester.gov.uk/egov_downloads/8_Dementia_Strategy_Update_Sept_2010.pdf

Barking and Dagenham's Health and Adult Services Select Committee carried out an in-depth review of local dementia services in response to the high incidence of the condition and relative lack of information available to patients and carers. Members looked in detail at dementia services covering prevention, identification, early intervention and treatment, living well with dementia, care in hospital and end of life care. Recommendations included awareness-raising, the development of a single point of contact for patients and carers and an integrated care pathway, and an equality impact assessment. The Committee has since received a report on progress on its recommendations: <http://www.cfps.org.uk/scrutiny-exchange/library/health-and-social-care/?id=2722>

Middlesbrough's Overview and Scrutiny Board carried out a review of dementia and dementia services in the area. Recommendations included the development of a specialised dementia service in Middlesbrough, the further development of advice services and dementia adviser posts, training and awareness raising across the local health and social care economy, including hospitals: <http://www.cfps.org.uk/scrutiny-exchange/library/health-and-social-care/?id=2722>

Oldham's Health and Adult Social Services Commission set up a Task and Finish Group to look at the provision of dementia services in Oldham with a view to informing the development of a Dementia Strategy. Recommendations included the development of an advocacy service, support for a 'Life Story' project, promotion of independent choice for people living with dementia and carers and provision of a 'seamless' service for under 65s moving into the over 65s group: <http://www.oldham.gov.uk/os-dementia.pdf>

Sandwell Council's scrutiny panel looked at care closer to home for older people with dementia, including how lower level early intervention might prevent people being hospitalised. As a result of the review's recommendations, a travelling dementia café is being opened to cover the six towns of the area: <http://cmis.sandwell.gov.uk/CMISWebPublic/Binary.ashx?Document=34414>

York's Health OSC carried out a dementia review and made recommendations on a Psychiatric Liaison Service, training for staff of

service providers, the role of carers, working with the voluntary sector and flexibility for dementia patients during hospital stays: <http://democracy.york.gov.uk/mgConvert2PDF.aspx?ID=16730>

References and resources

All-Party Parliamentary Group on Dementia (March 2010) *A Misspent Opportunity?*

http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1330

Alzheimer's Disease International (ADI) (2010), *World Alzheimer Report*: <http://www.alz.co.uk/research/worldreport/>

Alzheimer's Society

<http://www.alzheimers.org.uk/>

Alzheimer's Society (2009), *Counting the Cost*: http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=356

Alzheimer's Society (updated 2010), Position statement on website: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=412

Alzheimer's Society factsheet on younger people with dementia: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164

Bannerjee, S. (2009), *The use of antipsychotic medication for people with dementia: Time for action*, Department of Health: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108303

Dementia Action Alliance (2010), *National Dementia Declaration*: http://www.dementiaaction.org.uk/info/3/national_dementia_declaration

DH, (December 2010a) *The Operating Framework for the NHS in England 2011/12*

DH (December 2010b) *The NHS Outcomes Framework*

DH (September 2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827

DH (2009) *Living Well with Dementia: National Dementia Strategy*
<http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

Dementia Action Alliance
<http://www.dementiaaction.org.uk/site/>

HM Government (2011) Health and Social Care Bill
<http://www.publications.parliament.uk/pa/cm201011/cmbills/132/11132.pdf>

National Audit Office (2010) *Improving dementia services in England; an interim report*
http://www.nao.org.uk/publications/0910/improving_dementia_services.aspx

National Dementia Strategy Information Portal
<http://www.dementia.dh.gov.uk/objectivesAndResources/>

NICE *Dementia Quality Standard* <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/>

NICE– SCIE (2006) *Supporting people with dementia and their carers in health and social care*
<http://www.scie.org.uk/publications/misc/dementia/index.asp>

Royal College of Physicians (December 2010) *National Audit of Dementia (Care in Hospitals) Interim report*
<http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/nationalauditofdementia.aspx>

SCIE Dementia Gateway
<http://www.scie.org.uk/publications/dementia/index.asp>

Ten questions to ask if you are scrutinising services for people with dementia

1. How well developed are local strategies and partnerships?

The NDS identifies integrated work across health and social care as fundamental to effective support for people with dementia. Local areas need to develop a coordinated approach, ensuring that dementia services are driven at a senior level. The 2009 Implementation Plan required deputy regional directors for social care to complete baseline reviews of how local areas were implementing the objectives and to support PCTs and local authorities in developing local action plans by March 2010. The Dementia Portal provides regional information about local progress. Quality of information is highly variable, with South West, South East and North East providing detailed and useful information – others less so.

Objective 14 recommends that local areas should establish joint commissioning strategies. The NDS was supported by a Joint Commissioning Framework which includes a Joint Strategic Needs Assessment template and guidance on commissioning for each of the strategy's objectives (DH June 2009). Further to the updated implementation plan in September 2010, the DH is developing a commissioning pack for PCTs and local authorities.

A trained and effective workforce underpins all the measures in the NDS and is considered in detail in Objective 13. Two studies – on capacity and capability in the dementia workforce and on the current availability of accredited education and training – have been published (National Dementia Information Portal – workforce) and a new Workforce Advisory Group has been established to implement change, with a focus on local autonomy. The government intends to move away from a top-down model led by the DH to greater local accountability for decisions affecting workforce supply and demand. Local good practice requires the NHS and local authorities to work together to commission a trained and competent workforce using regional and local workforce development resources.

Good practice

- ◇ A senior lead for dementia in the council who raises the profile of dementia e.g. multi-agency/user/carer events, media initiatives.
- ◇ A senior lead in NHS trusts responsible for service improvements.
- ◇ Regular, senior attendance of all key agencies at a dementia 'board'.
- ◇ Involvement of people with dementia as well as carers in the

'board'.

- ◇ Current local strategy, joint commissioning plan, training plan and progress report in place and can be immediately accessed.

Example

Sussex Dementia Partnership (SDP) was established to improve dementia services county-wide, to develop new integrated care pathways to strengthen collaboration between partner agencies and to reduce unexplained variations in services. Achievements include the redesign of the dementia pathway to create rapid access to memory assessment, diagnostic counselling and links to other services including dementia advisers and intensive dementia-specific home care. An innovative system modelling approach identifies key investment options and is used to evaluate progress (DH 2011).

Questions

- ◇ Are the partnership arrangements for implementing the NDS led by senior representatives from the NHS and the council? How do these fit within wider partnership structures? How will they fit within forthcoming Health and Wellbeing Boards and with GP commissioning?
- ◇ How comprehensive is the area's action plan? Has it been updated? How does the local partnership intend to report on its progress?
- ◇ How do the initial baseline review, action plan and progress on the plan compare with peer localities? Are arrangements for benchmarking planned?
- ◇ What arrangements are in place to report on progress and will this be disseminated widely in the local area?
- ◇ Does the JSNA provide comprehensive information about the population distribution of people with dementia and carers? Does it also include information about people with dementia under 65 and those with dementia and learning disabilities or mental health problems?
- ◇ To what extent are people with dementia, their carers and their organisations involved in strategic planning and commissioning, and how are they supported to take on this role?
- ◇ Is a joint commissioning plan in place? Has it been costed on the basis of efficiency planning? Are there examples of redistribution of funding between the NHS, social care and the independent sectors?
- ◇ Do the NHS and the council understand the learning and development needs across all sectors and are measures being put in place jointly to establish core competencies in support for people with dementia across all relevant areas of the workforce?

References and resources

DH (2011) *Living well with dementia: a national dementia strategy good practice compendium*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

DH (February 2009) *NDS Implementation Plan*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103137

DH (June 2009) *Joint commissioning framework for dementia*

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_100837.pdf

DH (2009) *Living Well with Dementia: National Dementia Strategy*

<http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

National Dementia Information Portal - workforce

<http://www.dementia.dh.gov.uk/objectivesAndResources/workforce/>

Regional information on the Dementia Information Portal:

South West

<http://www.southwestdementiapartnership.org.uk/>

South East

<http://www.dementia.dh.gov.uk/inYourRegion/southEast/regionalNews/>

2. How good are local awareness, early identification and diagnosis?

Department of Health quality outcome: <i>'I was diagnosed early'</i>	People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.
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Improving public and professional awareness and understanding of dementia is Objective 1 of the NDS. Good-quality early diagnosis and intervention for all is Objective 2 of the NDS and one of the four priority objectives of the DH Quality outcomes framework for dementia. Early diagnosis and intervention in dementia improves outcomes and is cost-effective yet only between a third and a half of people with dementia ever receive a formal diagnosis. When diagnoses are made, it is often too late for those suffering from the illness to make choices. Further, diagnoses are often made at a time of crisis; a crisis that could potentially have been avoided if diagnosis had been made earlier.

In terms of the percentage of suitable patients receiving anti-dementia drugs, UK performance is in the bottom third in Europe, below almost all northern and western European nations and the average reported time to diagnose the disease in the UK is also up to twice as long as in some countries (NAO 2007).

The NAO report referred to above found that fear and ignorance of the disease are barriers to people and unpaid carers approaching their GP about suspected dementia, but also that the erroneous belief, widespread among GPs, that little can be done can hamper early diagnosis.

Although being diagnosed with dementia is extremely distressing it can also be a relief for people to understand the causes of problems they have been having and to get appropriate support and treatment. It can include prompt treatment of reversible symptoms such as memory problems and can prevent hospitalisation and reduce impairment.

The current evidence base suggests that up to 50% of dementia cases may have a vascular component (ie vascular dementia or mixed dementia). This holds out the possibility of preventing or minimising dementia by means of promoting better cerebrovascular health –

hence the slogan used in the National Dementia Strategy, “*what’s good for your heart is good for your head*”.

An early diagnosis of dementia followed by information and support can reduce outpatient costs by almost 30 percent (McCarten 2010).

Identification and early diagnosis requires that those who will come into contact with people who may develop dementia understand the signs and symptoms and know how to refer people to diagnostic and support services such as memory assessment services. Professionals who should have this awareness include GPs and other community and primary care professionals, social care providers and hospital staff. Currently only a third of GPs feel they have adequate training in diagnosis of dementia (DH September 2010) and 95 percent of hospitals do not have mandatory training in dementia awareness for all staff (Royal College of Psychiatrists 2010).

There is also a role for general awareness-raising of dementia issues in the population, including tackling the stigma associated with dementia. Backed by the Department of Health, the Alzheimer’s Society’s *Worried About Your Memory?* campaign prompts and helps people to consider if their forgetfulness, or that of a friend or relative, is due to just poor memory or the beginning of a medical problem and encourage them to seek medical advice (see references).

Currently, people with suspected dementia can be referred to a variety of places for confirmation of the diagnosis, including memory clinics, community mental health teams, and neurologists or old age psychiatrists in secondary care. The NICE-SCIE clinical guidelines on dementia say that memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia. The National Dementia Strategy recommends the establishment of a memory clinic in every PCT area.

Good practice

- ◇ A local dementia action plan with specific actions to raise awareness and facilitate early diagnosis and prevention
- ◇ Raising awareness and changing staff, including GP attitudes through person centred dementia care training
- ◇ Provision of locally based accessible location(s) for memory assessment services

Example

The Staveley Community Care Centre, Staveley, Derbyshire is the first

of a full network of high quality Community Care Centres in Derbyshire that will become the focal point for delivering services to older people with more complex levels of need. The Centre provides a location which is accessible to people living locally who can attend for memory assessment services, as well as good quality information for the general public, people with dementia and their carers. There will also be a wide range of other services, including intermediate care, in buildings that promote good, dementia friendly design and facilities.

Questions

- ◇ Does your area's dementia action plan include a section on raising awareness, early identification and diagnosis? Does it cover the points above?
- ◇ What commissioning resources are allocated to support for awareness-raising and diagnosis?
- ◇ What evidence is there of support by the local NHS and social services for general awareness raising and de-stigmatising of dementia (eg use of websites, support for voluntary sector awareness-raising campaigns, leaflets, talks in surgeries and locations where older people come together, targeted campaigns for other specific groups, eg public-facing public service employees, schools, cultural and religious organisations)?
- ◇ Is there a primary care dementia register for your area? How is it used?
- ◇ What training is commissioned on dementia awareness for health and social care professionals in your area, including primary and community care staff, staff of care homes and hospitals? How systematic is this, who is required and/or encouraged to attend it, how well is it monitored?
- ◇ Is there a single point of referral for all people with a possible diagnosis of dementia in your area, such as a memory clinic?
- ◇ What information is available on length of time between an initial visit to a GP and a diagnosis?
- ◇ What evidence is there that early identification, referral and diagnosis is increasing for your population both in terms of numbers of people and of timeliness?
- ◇ What provision is there for early intervention to support people with a new diagnosis of dementia in their homes?

References and resources

Alzheimer's Society, Worried About Your Memory? Campaign: <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200344>

Department of Health (2011), *Living well with dementia: a National Dementia Strategy*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123475.pdf

National Audit Office (NAO) (2007), *Improving services and support for people with dementia*, The Stationery Office: http://www.nao.org.uk/publications/0607/dementia_services_and_support.aspx

NICE guidance on specifying a memory assessment service: <http://www.nice.org.uk/usingguidance/commissioningguides/memoryassessmentservice/SpecifyingAMemoryAssessmentService.jsp>

McCarten, J. et al (2010), 'Changes In Outpatient Costs Following Screening And Diagnosis Of Cognitive Impairment', International Conference on Alzheimer's Disease: http://www.alz.org/icad/documents/abstracts/2010_early_detection.pdf

Royal College of Psychiatrists (December 2010) *National Audit of Dementia (Care in Hospitals) Interim report* <http://www.rcpsych.ac.uk/quality/quality accreditationaudit/nationalauditofdementia.aspx>

3. What information and advice is available locally?

<p>Department of Health quality outcome:</p> <p><i>'I understand, so I make good decisions and provide for future decision making'</i></p>	<p>Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.</p>
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Good-quality information for those with diagnosed dementia and their carers is Objective 3 of the NDS. Enabling easy access to care, support and advice following diagnosis is Objective 4.

It is important for the NHS and the organisations it works with to



provide good quality information on dementia and on the services available to support people with dementia and their carers – both before and after diagnosis and throughout the course of care. At a local level, OSCs can play an important role by undertaking a review of relevant information sources from the perspective of a user of services. These will include not only information about local advice, support and services in accessible locations and formats, but also signposts to national information, such as that provided by the Department of Health and the Alzheimer’s Society.

The Department of Health has supported the development of ‘information prescriptions’ in a number of areas including dementia. Information prescriptions can guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence. This type of resource is increasingly provided by local authorities as part of their provision of universal advice and information services. Many local authorities and NHS commissioners also support more direct and personal information and advice signposting services to enable people to know what support is available, whether they are entitled to it, whether it will cost them anything, where they can get it and so on. Many such services draw on the knowledge and experience of older people and carers themselves to act as “wayfinders” (Dorset) or “navigators” (Staffordshire) for those seeking information and advice.

The Alzheimer’s Society provides one-to-one and group support, dementia cafes, advocacy, befriending services and has also developed a network of dementia advisers.

The previous Government piloted a scheme of dementia advisers based in 22 sites around the country, as guides to help people with dementia and their families navigate their care and the support system available to them. Other pilot sites tested peer support networks offering different ways of providing patients and their carers with local practical and emotional support. In some areas, dementia ‘cafes’ have been set up, where people are able to meet others living with dementia. Referrals to dementia advisers and other support services may be made by GPs, Community Mental Health Teams or other health and social care professionals, or through self-referral.

Health and social care commissioners across the country have taken up some or all of these forms of providing information, advice and support.



Good practice

- ◇ Producing information, available in a variety of media (internet, GP surgeries, other locations where older people in particular are likely to be) about what dementia is, early symptoms, what to do if you are concerned and location of local dementia services
- ◇ Information prescriptions to guide people to sources of information and advice
- ◇ Schemes which draw on the experience and knowledge of older people and others as embedded members of communities to signpost the way to dementia services
- ◇ Support for peer support networks and/or dementia cafes.

Example

The Isle of Wight Council has developed a number of information prescription resources, including one for dementia, through its One Link health and wellbeing information website. By clicking and ticking through pages, people can find out about dementia and the local resources – statutory, community and private-sector – available for information and support.

Questions

- ◇ What information and advice services for people with dementia and their carers (including the examples described above) are commissioned by local NHS and social care commissioners?
- ◇ What information is available and where and how is it provided on:
 - what dementia is, its symptoms and impact?
 - how diagnoses are made and what they can tell patients, service users and their carers about their condition and prognosis?
 - how to stay healthy and active while living with dementia?
 - what treatment is available, what it can treat and how it will affect people's condition?
 - personal support for people at different stages of the condition and their carers from the NHS, social care services for those eligible for public funding and for self-funders?
 - support for younger people with dementia
- ◇ What evidence is there that information about, and referral to, advice and information services is appropriately and systematically provided by GPs, Community Mental Health Teams, hospitals, social services and other service providers with whom people with dementia may come in contact?

References and resources

Alzheimer's Society dementia adviser service: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=532

Department of Health (2011), *Living well with dementia: a National Dementia Strategy*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123475.pdf

Isle of Wight One Link website for information prescriptions: <http://www.iwight.com/onelink/>

NHS Information Prescription project website: <http://www.informationprescription.info/>

North Staffordshire and Stoke on Trent Dementia Advisory Service: http://www.approachstaffordshire.co.uk/go2/dementia_carer_older_people/

National Mental Health Development Unit, case study on Stockton Dementia Café: <http://www.nmhdu.org.uk/our-work/mhep/later-life/communities-of-interest/stockton-dementia-cafe/>

4. What appropriate treatment and support services are available?

<p>Department of Health quality outcome</p> <p><i>'I get the treatment and support which are best for my dementia, and my life'</i></p>	<p>Everyone living with dementia will receive the best dementia treatment and support, no matter who they are or where they live. They will feel that their personal needs have been appropriately assessed and that their treatment and potential consequences of treatment have been well planned and delivered in a coordinated way that is appropriate to their individual needs and preferences. They will be able to exercise personal choice in social care and ongoing support will be of a high quality.</p>
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A number of the objectives in the NDS cover treatment and support for people with dementia in the community (Objective 6), in hospitals



(Objective 8 – see section 5 below), intermediate care (Objective 9), housing support (Objective 10 – see section 6 below) in care homes (Objective 11 – section 7 below) and at the end of life (Objective 12 – see section 10 below).

Good treatment and support depends on good assessment and OSCs will want to assure themselves that assessments of health and social care needs are timely following diagnosis, are carried out in accordance with the principles of self-directed support, include the needs of both people with dementia and their carers, are joined up across health and social care and are regularly reviewed.

Community personal support services should include an appropriate range of flexible and reliable services to support people with dementia living at home and their carers. Support should range from early intervention to specialist home care services, which are responsive to the needs and preferences of individuals and their families. Such support should be part of an integrated approach across health and social care with evidence of good communication between all the professionals involved in the care of an individual at different stages of their condition.

Recent attention in relation to medical treatment of people with dementia has focused on the use of antipsychotic drugs, in response to widespread concern about their over-use for people with dementia. An independent report by Professor Sube Bannerjee, commissioned by the Department of Health and published in 2010 said there were 1,800 people each year dying from the effect of antipsychotic medication used to treat dementia but conferring little benefit (Bannerjee, 2010). The report said that the use of antipsychotic drugs could be reduced by two thirds over three years if action was taken. Recommendations also included additional training and support for GPs and staff of care homes on alternatives to drug treatments for behavioural problems arising from dementia. The government agreed to implement its recommendations.

The recent update of the National Dementia Strategy indicates that new data will be collected by the NHS Information Centre on the prescribing of antipsychotic medicines for people with dementia. GP commissioning consortia will be held to account and expected to show how they are reducing the prescribing of antipsychotic drugs.

The National Care Forum's guidelines on good practice in the care and treatment of dementia indicate that the following issues should be considered

– these could provide a helpful framework for a scrutiny review:

- ◇ assessment, care planning and review
- ◇ valuing communication
- ◇ access to services
- ◇ well-being and fulfilment
- ◇ staff support and development
- ◇ embedding a person-centred approach
- ◇ the care setting
- ◇ disseminating best practice

Good practice

Timely referrals to local assessment services following diagnosis
Integrated/joint assessment and care planning between health and social care

A wide range of support for people with dementia living at home and their carers

Training and support for GPs and staff of care homes on alternatives to drug treatments for behavioural problems arising from dementia

Evidence that the use of antipsychotic drugs is systematically monitored and is reducing.

Example

The Hampshire medicines management programme is 'work in progress' and is structured around:

1. identification and awareness raising with target groups: care homes, GPs and other prescribing practitioners, specialist clinicians, pharmacists, people with dementia and carers;
2. development and application of prescribing guidelines and supporting interventions; also implementation of measures of progress and evaluation;
3. engagement programme with all groups through training, education, and professional and peer support.

The agreed Hampshire guidelines for antipsychotic prescribing and managing behaviour problems for people with dementia have been disseminated to GPs, mental health clinicians, pharmacists and managers of care homes.

Questions

- ◇ How timely, integrated, person-centred, inclusive and systematic are assessments of the health and social care needs of people with

dementia and their carers? What evidence is there of regular review of needs?

- ◇ How is joint care and support commissioned by the NHS and local authority – how well does it support early intervention and specialist home care services as well as care provided in other settings discussed in sections 5 and 6 below?
- ◇ What evidence is there of a systematic and successful approach to reducing the use of anti-psychotic drugs in dementia care, including support and training for GPs and other professional staff in alternatives to drug treatments?
- ◇ How well does the commissioning and provision of dementia care cover the National Care Forum's themes listed above and the more detailed principles in its guidelines?

References and resources

Alzheimer's Society factsheet on the treatment of dementia with drugs: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=110

Bannerjee, S (2010), *The use of antipsychotic medication for people with dementia: Time for action* (Department of Health): http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108303

Bradford Dementia Group – University of Bradford centre for education and research on dementia care, which produces jargon-free good practice guides: <http://www.brad.ac.uk/health/Research/dementia/>

Dementia Services Development Centres – regional centres providing service development support on all aspects of dementia care services: http://www.dementia-voice.org.uk/Dsdc/DSDC_Network_Map.htm

Department of Health (2008) *Commissioning domiciliary care for people with dementia and their carers*: http://www.dementia.dh.gov.uk/library/downloads/Objectives_resources/objective14/DOH_NDS_commissioning_home_care.pdf

Hampshire guidelines on managing behaviour problems in people with dementia, developed by Professor Clive Holmes: <http://www.hampshirepartnership.nhs.uk/EasysiteWeb/getresource.axd?AssetID=12068&type=Full&servicetype=Attachment>

Department of Health (2011), *Living well with dementia: a National Dementia Strategy*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123475.pdf

Living well with dementia case example - four local authorities jointly commission special support workers for people with dementia. This case study shows how they manage these arrangements: [http://www.dementia.dh.gov.uk/library/downloads/Objectives_resources/objective14/Obj_14 - Case example - Joint Commissioning Somerset Supporting People .doc](http://www.dementia.dh.gov.uk/library/downloads/Objectives_resources/objective14/Obj_14_-_Case_example_-_Joint_Commissioning_Somerset_Supporting_People_.doc)

National Care Forum (2007), *Key principles of person-centred dementia care*: <http://www.nationalcareforum.org.uk/content/Key%20principles%20of%20person-centred%20dementia%20care.pdf>

5. How good is care for people with dementia in hospital?

<p>Department of Health quality outcome</p> <p><i>'I am treated with dignity and respect'</i></p>	<p>People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.</p>
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The treatment of people with dementia in general hospital is Objective 8 of the NDS. People with dementia have worse outcomes in terms of length of stay, mortality and institutionalisation. Lack of understanding and leadership can lead to poor care such as failure to control pain, insufficient nutrition and hydration and poor access to specialist mental health assessment.

The problem is significant both in human and budgetary costs. Up to 70% of people in acute beds are older people, and up to half of these may have a cognitive impairment including dementia. The NAO has estimated the excess cost may be more than £6 million a year in an average general hospital (DH 2009). Discharge arrangements may also be problematic. A study by the Alzheimer's Society showed that 36% of people with dementia admitted to hospital from their own home

were later discharged to residential care. Longer stays in hospital can lead to deterioration – the Alzheimer’s Society estimates that national savings for the NHS of £80 million could be achieved by discharging people a week earlier. Better access to supported discharge arrangements are required, with funding transferred from acute care to social or community health care. Improving access to intermediate care is Objective 9 of the strategy.

Improving care in hospital has been identified as one of the four key priorities in the latest implementation plan (DH September 2010) and there is clearly much more to be done as can be seen in the interim report of findings from the National Audit of Dementia Care in General Hospitals (Royal College of Psychiatrists December 2010). This audit of 8,000 patients in 200 hospitals found:

- ◇ 95% of hospitals do not have mandatory training in dementia awareness for all staff whose work is likely to bring them into contact with patients with dementia
- ◇ Although 96% of hospitals said nutritional assessments of patients with dementia were standard practice, about a third of patients did not have an assessment recorded during their admission.
- ◇ Eight out of ten hospitals had no system to ensure that ward staff were aware of a patient’s condition and how it might affect their care.
- ◇ Only four out of ten patients received a formal mental status test at hospital admission.
- ◇ A third of patients referred to in-hospital psychiatry liaison services had not been seen after 96 hours.

The report provides the basis for hospitals and health professionals to assess local performance to make improvements ahead of the full audit which will report in December 2011.

Good Practice

- ◇ An identified senior hospital clinician with responsibility for making improvements, including establishing an explicit care pathway for the management of people with dementia.
- ◇ Commissioning specialist liaison older people’s mental health teams to work in general hospitals.
- ◇ Core competencies for all hospital staff in contact with people with dementia.
- ◇ Arrangements to ensure the improvement of nursing care for people with dementia on hospital wards.
- ◇ Improved discharge arrangements with a focus on re-ablement

including intermediate care.

Example

University Hospitals of Leicester NHS Trust conducted an organisational drive to improve services for people with dementia and their carers (DH 2011). Achievements include:

- ◇ 600 staff completed person centred dementia care training
- ◇ a patient profile to promote better communication and understanding
- ◇ recruiting mealtime assistant volunteers
- ◇ a trust-wide dementia care group to develop a clinical pathway.

Questions

- ◇ How is the local NHS performing on improvement measures 1-4 identified above?
- ◇ Has the LINK (Healthwatch) or other patient groups identified any local concerns about care of people with dementia in hospital?
- ◇ How comprehensive is the access of people with dementia to reablement services including intermediate care?
- ◇ Does the area understand the level of referral of people with dementia from hospital to care homes from hospital, and, if excessive, are measures in place to address this?
- ◇ What funding arrangements have taken place between acute care and community health/social care?

References and resources

Alzheimer's Society (November 2009) *Counting the Cost: caring for people with dementia*

http://alzheimers.org.uk/site/scripts/news_article.php?newsID=579

DH (2011) *Living well with dementia: a national dementia strategy good practice compendium*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

DH (2009) *Living Well with Dementia: National Dementia Strategy*

<http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

National Dementia Strategy Information Portal – hospital
http://www.dementia.dh.gov.uk/objectivesAndResources/General_Hospital/

Royal College of Psychiatrists (December 2010) *National Audit of Dementia (Care in Hospitals) Interim report*
<http://www.rcpsych.ac.uk/quality/quality.accreditationaudit/nationalauditofdementia.aspx>

6. How are people with dementia supported in living at home?

DH quality outcome: <i>'I know what I can do to help myself and who else can help me'</i>	People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.
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Improved community personal support services is Objective 6 of the NDS. Nearly two-thirds of people with dementia live in the community. Specialist NHS dementia care is delivered mainly through GPs and mental health trusts, which may provide services such as Memory Services and/or Community Mental Health Teams (CMHTs). As the disease progresses, people with dementia may need help at home, including domiciliary care. New models of housing and assistive technology, such as sensors that monitor people's movements, are increasingly being used to help people with dementia to remain living in their own homes.

Providing care at home for people with dementia can be both challenging and rewarding. It requires a co-ordinated approach by health and social care professionals working co-operatively with people living with dementia and their carers. To avoid distressing people with dementia, continuity and consistency of care arising from good coordination are important but currently evidence suggests that they are rarely available. Evidence shows that people with dementia



and carers would prefer to have one health or social care professional as their main contact (NAO 2007). The type of care provided at home should be based on knowledge of the person with dementia, their life and their experience. Support at home from a specialist service provider can transform the lives of a person with dementia and their family.

The Department of Health recommends CMHT as the appropriate route into co-ordinated services for older people with mental health needs, but CMHTs are still not all fully integrated across health and social care. The NAO report referred to above found significant gaps in CMHTs' ability to access specialist skills and services, including financial barriers to providing day care and respite care – vital for support of carers as well as for people with dementia themselves (see section 9 below). There was also a shortage of appropriate services for people with young-onset dementia and of appropriate services for people from black and minority ethnic groups and those with learning difficulties (people with Down's Syndrome, for example, are more prone to developing dementia than the rest of the population).

The NAO also found problems with the quality of domiciliary social care for people with dementia, including failure to train care workers in dementia care and lack of staff continuity. More recently, an Alzheimer's Society survey found that 50% of people with dementia who lived at home were not getting the care and support they needed – in some situations left bedridden, with unchanged incontinence pads and malnourished (2011).

One of the biggest barriers to enabling people with dementia to have more control over their lives is an overly cautious approach to risk. A 'risk enablement' approach has been developed by researchers and practitioners, based on the idea of balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether. For example, the risk of getting lost if a person with dementia goes out unaccompanied needs to be set against the possible risks of boredom and frustration from remaining inside. The Department of Health has recently published guidance on approaches to risk for people with dementia which discusses how a positive approach can enable people to live independently at home for longer (DH November 2010).

One of the new developments to assist people living with dementia to manage risk while living as independently as possible at home is the use of assistive technology. There are now a wide range of technological devices, solutions and services that may be of benefit to people with dementia and those who help care for them. Many of these

devices are 'passive' in that the person does not need to press a button to activate them, which is often helpful for people with memory difficulties such as dementia. Examples of passive devices include a light that automatically switches on when a person enters a room, a bath plug that releases water if the bath becomes over-full or a sensor that alerts a carer if someone exits a room in the middle of the night. However, if assistive technology does not meet the individual needs and preferences of the person it may be ineffective or may even cause additional confusion or distress. There may also be ethical issues involved in the use of assistive technology, for example where a person lacks the capacity to give their informed consent. OSCs should be aware of this technology and the issues it gives rise to for people with dementia and understand how it is being used by commissioners in their own area.

The traditional response to accommodation for people with dementia has been a nursing or residential home with intensive support, often involving separating couples when one of them develops dementia. However, the NDS and the National Strategy on Housing for an Ageing Society (CLG, 2008) note that new models of housing services can help people live more independently with their families and prevent or delay the use of more costly, and sometimes disabling, 'downstream' services. These models use both assistive technology, building design and other forms of design, some very 'low tech', such as labels and pictures of familiar objects, to help people understand and interact with their environment in carrying out the processes of daily living. Examples include the Housing 21 programme and the Shore Green extra care housing scheme in Manchester referenced below.

Good practice

- ◇ A cross-sectoral and cross-council approach to planning, developing and adapting housing for people with dementia, including planning, housing, environmental services, social services and the NHS
- ◇ Arrangements between the NHS and social services so that a single health or social care professional is the main source of contact with services for each individual with dementia
- ◇ Training in dementia care and staff continuity of domiciliary care workers
- ◇ Training in dementia care and awareness of services available for Community Mental Health Teams
- ◇ Evidence of a positive approach to risk based on DH guidelines
- ◇ The use of new developments in technology and telecare with appropriate choice and involvement of people with dementia

- ◇ Evidence of specialist care planning for people with young-onset dementia, people from black and minority ethnic groups and those with learning difficulties

Example

Shore Green is a 10 unit specialist extra care scheme in Baguley, South Manchester. The scheme offers flexible and responsive personal care support services for older people with dementia and a range of memory loss conditions. It aims to enable tenants to maintain their independence and enhance their quality of life for as long as possible. Each person has their own tenancy and is encouraged to exercise as much choice and control over the care and support they receive as possible. The scheme is specially designed to provide a safe yet welcoming environment and uses assistive technology to help reduce instances of wandering and appliances being left on.

Questions

- ◇ What support is provided in your area to enable people with dementia to live full and active lives at home for as long as possible?
- ◇ Is the Community Mental Health Team fully integrated across health and social care and does it act as the co-ordinator of home services for people with dementia? What evidence is there of co-ordination between the CMHT and others, such as GPs, who may be providing care to people with dementia? Is there provision for people with dementia to have one health or social care professional as their main contact?
- ◇ What kind of domiciliary social care is commissioned for people with dementia? How specialised is it and what training and professional development is specified in commissioning contracts? What evidence is there that providers are aware of dementia issues and new thinking and developments in this area?
- ◇ What support is there for younger people with dementia living at home?
- ◇ What support is there for people from ethnic minorities with dementia in the community?
- ◇ Is there a clearly understood approach to risk in planning services for people with dementia, based on DH guidelines?
- ◇ How is your authority and its partners using assistive technology to support people with dementia? How is its effectiveness assessed? How are ethical issues discussed and resolved?
- ◇ What new models of housing are being developed to enable

people with dementia to live at home with their families? Which local partners are involved?

References and resources

Alzheimer's Society (2011) *Support. Stay. Save. Care and support of people with dementia in their own homes*

http://alzheimers.org.uk/site/scripts/news_article.php?newsID=896

AT dementia – information on assistive technology for people with dementia, including discussion of ethical issues: [http://](http://www.atdementia.org.uk/editorial.asp?page_id=25)

www.atdementia.org.uk/editorial.asp?page_id=25

Communities and Local Government (2008), *National Strategy for Housing in an Ageing Society, Lifetime Homes, Lifetime*

Neighbourhoods: <http://www.communities.gov.uk/publications/housing/lifetimehomesneighbourhoods>

DH (November 2010), *'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia*: [http://](http://www.puttingpeoplefirst.org.uk/library/Resources/JIPSE/Nothing_Ventured_Nothing_Gained.pdf)

www.puttingpeoplefirst.org.uk/library/Resources/JIPSE/Nothing_Ventured_Nothing_Gained.pdf

DH (2011) *Living well with dementia: a national dementia strategy good practice compendium*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

Housing 21 housing programme of 'smart flats' for people with dementia:

www.housing21.co.uk/index.php/download_file/-/view/168/

Manchester City Council – case study on Shore Green extra care housing for people with dementia: [http://www.idea.gov.uk/idk/core/](http://www.idea.gov.uk/idk/core/page.do?pagelid=22962034)

[page.do?pagelid=22962034](http://www.idea.gov.uk/idk/core/page.do?pagelid=22962034)

National Audit Office (2007), *Improving services and support for people with dementia*: [http://www.nao.org.uk/publications/0607/](http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx)

[support_for_people_with_dement.aspx](http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx)

NICE-SCIE (2007), *Dementia: guideline on supporting people with dementia and their carers in health and social care*: [http://](http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf)

www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf

7. What is the quality of life for people with dementia in care homes?

DH quality outcome: <i>'I can enjoy life'</i>	People living with dementia will be well supported in all aspects of living with dementia leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia (DH September 2010).
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Although being supported to remain at home or in a housing facility such as extra care housing is the preference for most people with dementia, in some situations this will not be possible. For some, living in a care home provides the right balance between safety and independence, and access to activity and an understanding community. Unfortunately, good quality care is far from the norm – failure to communicate, over-use of antipsychotic medication to manage behaviour, lack of stimulation, inadequate nutrition, and lack of support from specialist mental health teams – is well documented. Objective 11 of the NDS concerns improving care in care homes.

A third of people with dementia live in care homes; up to 75% of people in non specialist homes have dementia, rising to 90-95% in homes for the elderly mentally infirm. The NDS indicates that the increase in the population with dementia means that although a greater proportion of people will be supported at home, the number of those requiring a care home placement is likely to remain similar to the current position.

There is a considerable body of evidence for homes to draw on to provide excellent support. For instance the SCIE dementia gateway provides practical information on matters such as advance care planning, swallowing, managing agitation, responding to repetition, managing toileting problems etc. However, individual homes can only do so much to provide good quality care. They need to be supported within the wider system of the NHS, council and the voluntary sector. In particular, homes need to be supported by specialist mental health services that provide regular interventions rather than ad hoc or crisis support.

Good practice

- ◇ Low rates of delayed hospital discharge particularly for people with advanced dementia.
- ◇ A mental health specialist outreach service – care homes have regular contact.
- ◇ The NHS has undertaken a review of anti-psychotic medication in care homes and has plans to reduce prescriptions if necessary.
- ◇ Residents have personal support plans with individual needs addressed with, for instance, increased staffing at meal times and individualised use of assistive technology.
- ◇ Homes have a varied programme of activities that operates consistently (not just a timetable on a wall); homes feel friendly and people interact.

Example

Following concerns about quality, Worcestershire County Council developed a Dementia Care Standard for homes. Activity includes leadership courses for owner/managers, a dementia diploma for managers, an increase in meaningful activity for residents, and a more personalised service. Formal evaluation is to follow but initial results point to less distress, boredom, agitation and use of medication and improved relationships and self esteem (DH 2011).

Questions

- ◇ Does the Joint Strategic Needs Assessment include a projection of the future need for capacity in care homes? How does the joint commissioning strategy address this need?
- ◇ Are the NHS, the council and the independent sectors working together in a recognised partnership to improve care?
- ◇ To what extent is there a local system of specialist mental health support for care homes? Does this provide regular support such as assessment on admission and a rapid response to problems?
- ◇ What measures are in place to improve training and education in all sectors?
- ◇ Do specifications and contract monitoring arrangements cover best practice in dementia care?
- ◇ How have local care homes been rated by the Care Quality Commission, and by any local monitoring arrangements? Have LINKs (Healthwatch) or advocates raised any concerns?
- ◇ Do local homes provide regular activities to stimulate people with dementia such as art, music and Life story work? Is there a rich

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- physical environment to aid orientation with assistive technology for prompts, reminders and communication?
 - ◇ Does the NHS know the pattern of prescription of antipsychotic drugs? Are GPs involved in reducing this? Do homes routinely use non pharmacological behaviour management strategies?

References and resources

Assistive technology for dementia

<http://www.atdementia.org.uk/>

DH (2011) *Living well with dementia: a national dementia strategy good practice compendium*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

DH (2009) *Living Well with Dementia: National Dementia Strategy*

<http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm>

Lifestory website

<http://lifestorynetwork.org.uk/>

National Dementia Information Portal – care homes

http://www.dementia.dh.gov.uk/objectivesAndResources/Care_Homes/

SCIE Dementia Gateway

<http://www.scie.org.uk/publications/dementia/index.asp>

8. How are people with dementia involved in their communities and civil society?

<p>DH quality outcome:</p> <p><i>'I feel part of a community and I'm inspired to give something back'.</i></p>	<p>People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research (DH September 2010).</p>
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Peer support is Objective 5 of the NDS, and is one of the two topics

chosen to be piloted in the demonstrator site programme. In the consultation on the strategy, people with dementia and carers had expressed the view that peer support networks were valuable for promoting confidence and coping strategies to help them live well with dementia.

Projects in the demonstrator site programme aim to provide practical and emotional support, reduce social isolation, promote self-care, and enable people with dementia to take an active role in shaping services (National Dementia Information Portal – peer support).

While some areas have excellent peer support services these are far from widespread and, where they exist, can tend to focus on carers. There is clearly significant potential for development. Synergies exist between other civil society and user-led initiatives, such as those developed through the Partnerships for Older People Projects (POPPS) (DH January 2010) and LinkAge Plus pilots (DWP 2009). The emphasis on self help and on helping others fits within the government policy for Big Society. The Cabinet Office has undertaken a tender exercise for a national partner to implement the programme in which community organisers will be trained to encourage social action, particularly in deprived areas. Alongside the *Vision for Adult Social Care* (DH November 2010a) a report was published linking the Building Community Capacity Programme with self directed support (DH November 2010b).

While such developments are at an early stage, the message that can be taken from the NDS is that people with dementia can participate in and benefit from such initiatives. Furthermore there is significant evidence from POPPs, LinkAge Plus and Building Community Capacity evaluations that these initiatives can be cost effective. For instance community navigators could save £900 for every £300 spent (DH November 2010).

Good practice

- ◇ Memory cafes which provide an informal opportunity for people with memory problems and carers to meet up socially, with opportunities for information, involvement in shaping services and wider social activities.
- ◇ Learning networks and web-based networks involving people with dementia
- ◇ Individual befriending/peer support.
- ◇ Opportunities for people with dementia to be involved in training staff and expert patient initiatives.

- ◇ The above models targeted at specific groups e.g. younger people with dementia, those from BME communities, people in rural areas.
- ◇ Services led by people at the early stages of dementia.

Example

Tom's Club in Haringey is a form of Alzheimer Café for people with dementia and their carers, supplemented by dementia expertise from the Admiral Nursing team. It provides both therapeutic contact and social activities. Parallel sessions allow carers and cared for to have separate time if needed. Numbers attending have steadily increased over two years and evaluation is very positive. Local businesses provide much of the catering and hospitality (DH 2011).

Questions

- ◇ What is the extent of peer support initiatives in the area and how are these supported?
- ◇ Does the area promote user-led initiatives by people at the earlier stages of dementia?
- ◇ Has the area considered costs and benefits of community capacity building relating to older people and people with dementia?
- ◇ What steps is the area taking to support building community capacity? How is this being linked to older people, and specifically, people with dementia?
- ◇ How are people with dementia and their carers involved in service planning, delivery and decision making?

References and resources

DH (2011) *Living well with dementia: a national dementia strategy good practice compendium*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

DH, November (2010a), *A vision for adult social care: capable communities and active citizens.*

http://www.dh.gov.uk/en/Aboutus/Features/DH_121664

DH, November (2010b) *Practical approaches to improving the lives of disabled and older people through building stronger communities*.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121668.pdf

DH, January (2010) *National Evaluation of Partnerships for Older People Projects*.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111240

DWP (2009) *LinkAge Plus national evaluation*.
<http://campaigns.dwp.gov.uk/asd/asd5/rports2009-2010/rrep572.pdf>

9. How are carers of people with dementia supported?

<p>DH quality outcome:</p> <p><i>‘Those around me and looking after me are well supported ‘</i></p>	<p>People living with dementia will feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.</p>
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Implementing the Carers’ Strategy is Objective 7 of the NDS. It points out that family carers are the most important resource available for people with dementia. There are estimated to be 600,000 people in the UK acting as primary carers for people with dementia and carers are believed to save the public purse £6 bn every year (Alzheimer’s Society, 2007).

Looking after someone with dementia at home can be distressing, and is almost always hard work. But many carers say that they also get satisfaction from helping the person. Many carers are older people themselves, although young carers should not be forgotten in scrutiny reviews. Caring for someone with dementia is likely to effect the health, family life, leisure, employment and finances of carers (NHS Information Centre December 2010).

Health and social care managers should ensure that the rights of carers to receive an assessment of needs, as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act

2004, are upheld. They can be supported through an agreed plan to support the important role they play in the care of the person with dementia. They should also be thought of as 'partners in care' by professional health and care staff, who should involve them in the care planning process while respecting the right to privacy and autonomy of the person with dementia.

DH guidance on support for carers suggests that there are four main areas of help in which carers will need support:

- ◇ medical – from GPs and other practice staff
- ◇ personal – through respite care and breaks from caring to pursue their own interests and family and social lives; keeping fit; peer support from other carers; and in sharing responsibility for the caring role
- ◇ practical – including help with nursing care, domiciliary services and equipment; carers also report that they find great value in services that fall outside what is traditionally considered 'care', for example help with DIY and gardening (Alzheimer's Society website)
- ◇ financial and legal – including benefits advice; support in dealing with personal budgets and direct payments; advice on financial planning; advice on legal matters such as Lasting Power of Attorney and capacity issues.

Support for carers should include good-quality, personalised breaks from the caring role. Overnight respite care has traditionally taken the form of residential/nursing home care. But a growing number of Shared Lives schemes (formerly known as adult placements) are beginning to support people with dementia. Two such are the Time to Share scheme in Falkirk and the SWAPS scheme in the south west of England (referenced below) which provide short breaks for people with dementia in the homes of Shared Lives carers.

However, things can sometimes become too much for a carer and the NICE-SCIE guideline states that carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.

Good practice

- ◇ Information specifically for carers about local dementia and carer services
- ◇ Evidence of appropriate involvement of carers in assessment, care planning and review
- ◇ Community support and peer support for carers
- ◇ Provision of emergency and planned respite care

- ◇ Psychological and other wellbeing therapies for carers

Example

Oxfordshire County Council's OXCARE service runs a course for people who provide unpaid care, such as a friend or family member. A rolling programme of training events for unpaid carers is available through the Oxfordshire Carers Centres. Course topics include stress management and coping with challenging behaviour.

Questions

- ◇ How are carers involved in the planning of care for the person they care for?
- ◇ What evidence is there that all carers of people with dementia receive their own assessment and care plan? How well integrated across health and social care are such plans, including support from GPs? How systematically are they reviewed?
- ◇ What general and peer support services are available for carers of people with dementia in your area? How well are they used and by whom? How are carers involved in their design and development?
- ◇ What personal support is available for carers, including respite care and breaks, domiciliary care and other forms of support in the home such as DIY and gardening? What charges if any are made for this support and how flexible and affordable is it?
- ◇ What support is available for young carers?
- ◇ What financial and legal support is available for carers?
- ◇ What psychological therapy is available for carers? How is this commissioned?

References and resources

Alzheimer's Society website, carer support pages: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=546

Carers UK: <http://www.carersuk.org>

DH (2007), *Who cares? Information and support for the carers of people with dementia*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_078091.pdf

NHS Information Centre (December 2010), *Survey of Carers in Households, 2009/10*: http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/carersurvey0910/Survey_of_Carers_in_Households_2009_10_England.pdf

Shared Lives respite care schemes:
<http://www.communitycare.co.uk/Articles/2010/10/28/115701/good-practice-time-to-share-scheme-for-dementia-patients.htm>

10. How good is care for people with dementia at the end of life?

DH quality outcome: <i>'I am confident my end of life wishes will be respected. I can expect a good death'.</i>	People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well coordinated and planned so that they die in the place and in the way that they have chosen.
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Objective 12 of the NDS concerns improving end of life care (EOLC) for people with dementia. People with dementia are 4-6 times more likely to die with a given disorder (e.g. heart condition) than the general population with that disorder. There is significant evidence that many people experience poor end of life care, with a lack of comfort and dignity. Communication difficulties mean that untrained staff may misinterpret pain as aggression – people with dementia receive significantly less access to analgesia (DH 2010). They are also less likely to access hospice support, and are much more likely to die in hospital or care homes than at home (NEOLCIN November 2010). People with dementia tend to have a less predictable decline, making prognosis more difficult, while deterioration in communication skills prevents people expressing preferences late in the care pathway. Even trained workers may often procrastinate in discussing preferences until it is too late (University of Bath 2010).

Good practice involves an integrated approach to EOLC in dementia with the wider EOLC strategy, using the Gold Standards Framework. Also necessary is a comprehensive range of 24:7 community health and social care services in which staff are aware of and can address the end of life care needs of people with dementia.

NICE has produced commissioning guidance for end of life dementia care. The SCIE dementia gateway gives practical advice on matters such as nutrition for the dying and supporting carers in bereavement. The National Council for Palliative Care provides a series of useful documents such as advance care planning in health and social care, and quality markers for linking dementia with local EOLC strategies.

Good practice

- ◇ Carers have access to emotional support when the person they have cared for dies.
- ◇ All relevant staff in hospital and care homes have received training in pain relief and nutrition.
- ◇ The area has undertaken a place of end of life audit and is implementing a plan for more people to die in their place of choice.
- ◇ Admiral nurses operate in the area.

Example

Peterborough Palliative Care in Dementia Group provides a peer support network across primary and secondary care and care homes. Reporting to the End of Life Steering Group, it has provided training, events and guidance geared at improving end of life care. As well as increased confidence in care staff in supporting people who are dying, there have been a decrease in emergency hospital admissions and an increase in people dying in care homes rather than hospital from around 55% to 75% (DH 2011).

Questions

- ◇ Is there a joint plan for improving the quality end of life care for people with dementia? Is this joined up with the area's wider End of Life Strategy? What progress is being made?
- ◇ Is there an integrated approach to commissioning personalised services across health, care and the independent sectors which can provide the opportunity for people with dementia to die well at home?
- ◇ Are relevant workers, e.g. social workers, proactive in suggesting that people with dementia and carers could consider EOL preferences while they still have capacity to do so? Is full use being made of Mental Capacity Act planning tools to maximise people's control e.g. advance care planning, lasting power of attorney.
- ◇ What measures are in place to ensure that staff in hospitals, hospices and care homes understand the care needs of people

- with dementia who are dying, particularly pain relief and nutrition? Is this monitored?
- ◇ What support is provided to carers, if required, through death and bereavement?
 - ◇ Are there a range of services across all settings geared-up to providing appropriate support? Is this included in service specifications? Are there clear referral pathways promoting ease of access to people with dementia?

References and Resources

DH (2011) *Living well with dementia: a national dementia strategy good practice compendium*

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

Gold standards in end of life care

<http://www.goldstandardsframework.nhs.uk/>

National Council for Palliative Care – various publications

<http://www.ncpc.org.uk/publications/freedownloads.html>

NDS Dementia Information Portal – end of life care

http://www.dementia.dh.gov.uk/objectivesAndResources/End_of_Life_care/

NEOLCIN (National End of Life Care Intelligence Network), November 2010, *Deaths from Alzheimer's disease, dementia and senility in England*.

<http://www.endoflifecare-intelligence.org.uk/news/default.aspx>

NICE, 2010, *Commissioning guidance for end of life care and dementia*.

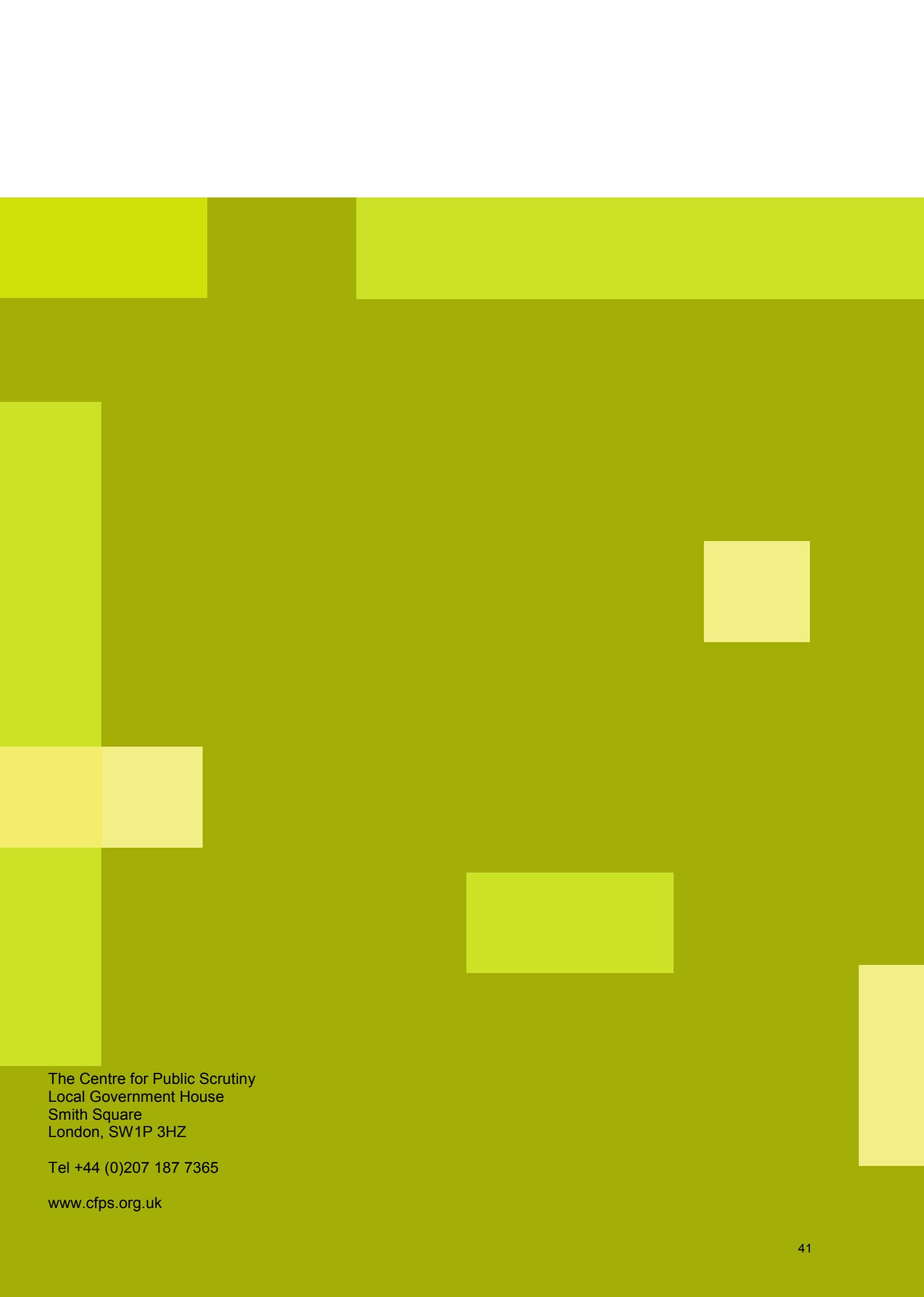
<http://www.nice.org.uk/usingguidance/commissioningguides/eolcforpeoplewithdementia/eolcforpeoplewithdementia.jsp>

SCIE dementia gateway – end of life care

<http://www.scie.org.uk/publications/dementia/index.asp>

University of Bath, 2010, *Recommendations for end of life care in dementia*.

http://www.dementia.dh.gov.uk/objectivesAndResources/End_of_Life_care/



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