In the UK, an estimated 750,000 people suffer from Alzheimer’s and other dementia disorders. Dementia makes independent living either difficult or impossible in the later stages. As the UK population ages, the number of cases are predicted to rise over the next two decades placing a significant demand on health and social services. This POSTnote reviews current understanding of the causes of dementia, the hopes for interventions, and the UK’s current position in terms of handling future demand for services.

Background
What are dementia-related disorders?
Dementia is a syndrome that in most cases is caused by an underlying disease of the brain and loss of brain tissue. There are several diseases which give rise to dementia, such as Alzheimer’s and Parkinson’s with dementia (Box 1), known as subtypes. Functions affected include memory, orientation, thinking, comprehension, calculation, judgement, learning and language. Dementia is a progressive disorder and is accompanied by deterioration in emotional control, social behaviour and loss of independent function and decision-making. The cause, course and symptoms of dementia depend on numerous factors. It is difficult to distinguish between some of the different subtypes, to predict the timescales over which a person’s cognitive abilities decline, and what behavioural symptoms a sufferer may experience. At present, no biological interventions are available which alter or reverse the underlying degeneration of brain cells.

Dementia in an ageing population
The risk of developing dementia is strongly associated with ageing, although inheritable early-onset dementia does occur very rarely in people under 65 years. Population studies show that the prevalence (number of cases) roughly doubles every 5 years over the age of 60 (Table 1). The UK population is projected to increase to 69.3 million in 2051 from 60.5 million in 2006. Should prevalence rates remain unchanged over the next few decades, and as the population ages, the total number of dementia cases could more than double, from 750,000 in 2006, to 1.8 million in 2051 (Figure 1).

Table 1: Prevalence rates of dementia by age

<table>
<thead>
<tr>
<th>Age-group (years)</th>
<th>Prevalence of dementia (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-64</td>
<td>0.9</td>
</tr>
<tr>
<td>65-69</td>
<td>1.5</td>
</tr>
<tr>
<td>70-74</td>
<td>3.6</td>
</tr>
<tr>
<td>75-79</td>
<td>6.0</td>
</tr>
<tr>
<td>80-84</td>
<td>12.2</td>
</tr>
<tr>
<td>≥85</td>
<td>24.8</td>
</tr>
</tbody>
</table>

Figure 1: Projected percentage of UK population over 65 years old, and estimated total cases of dementia

Diagnosis and care of people with dementia
Currently, dementia is diagnosed through a series of tests to assess cognitive decline. In the ‘very mild’ stage, suspicion is raised when someone has trouble with memory, learning and, perhaps, mild personality changes. A formal diagnosis maybe made when there is impairment of social or occupational function. Gradually one or more ‘activities of daily living’ such as dressing or bathing are also affected. The moderate stage sees growing impairment of language and memory and increased reliance on a carer. Behavioural disturbance and psychological symptoms can happen at any stage of the illness. The greatest impact on sufferers, carers and society is concentrated in those in the severe stages (~17-28% of people with dementia over 65). Dementia is a key factor in the need for nursing-home placement; 62-74% of residents in care institutions have dementia.
Dementia is immensely important to UK health and social care policy. For instance, doctors, who have to decide what to tell MCI patients about this subset. Uncertainty over MCI poses ethical issues for this group, as some techniques may predict ~80% of MCI patients going on to develop dementia; and the time scale over which this might occur. Considerable confusion remains over these. For example, some definitions of MCI include almost all people over 65, and others almost none. Some studies suggest that 12-15% of MCI patients will develop mild dementia each year, but this may not be applicable in the general population. New diagnostics (Box 2) may help to target interventions to this group, as some techniques may predict ~80% of this subset. Uncertainty over MCI poses ethical issues for doctors, who have to decide what to tell MCI patients about their increased risk of dementia.

Interventions
There are a variety of potential interventions for dementia. These include drugs (Box 3), non-pharmacological interventions (e.g. cognitive retraining; information and advice), and supporting those affected to live more independently using assistive technology (Box 4). Drugs that treat cognitive symptoms of Alzheimer’s disease have been in the limelight due to recent guidance on their use by the National Institute of Health and Clinical Excellence (NICE).

NICE appraisal of current Alzheimer’s drugs
Four drugs can be used to treat the cognitive symptoms of Alzheimer’s disease. Each costs the NHS ~£1,000 per patient per year, or £50 million per year in total. An
appraisal in 2006 NICE recommended that: treatment of mild and moderate Alzheimer’s. In a new appraisal by NICE in 2001 recommended the use of the drugs. There was criticism for not factoring in: did not place sufficient value on wider benefits of using A number of bodies appealed against the 2006 Response to NICE recommendations.

Emerging drugs
New drugs are based on firmer knowledge about the disease mechanism, targeting the root cause of brain degeneration rather than symptoms, but take 15-20 years to develop. There are around 640 drugs under various stages of development for neurodegenerative disorders. A handful of these target Alzheimer’s disease. Possible targets include ‘amyloid plaques’ and ‘protein-tangles’ (Box 1). Drugs targeting such features are in late stages of clinical development, with some results expected in 2007 or 2008. A ‘vaccine’ is also under development, and other drugs highlighted in population studies may also prove beneficial.

Box 3. Dementia drugs.

Current drugs
Four drugs are currently used to treat cognitive symptoms in Alzheimer’s Disease. They interact with mechanisms that allow brain cells (neurons) to communicate with each other. Three, called acetylcholinesterase (AChE) inhibitors, help to maintain levels of the signalling molecule acetylcholine by delaying its breakdown. The drugs are based on work suggesting that depletion of this molecule and associated loss of ‘cholinergic neurons’ are an underlying factor in Alzheimer’s. A fourth drug, memantine, blocks the action of another signalling molecule, high levels of which are implicated in neuronal dysfunction. Many clinical trials suggest the drugs provide modest cognitive benefits for ~40% of Alzheimer’s sufferers for ~6-18 months, but do not slow down the underlying disease. Some trials suggest wider benefits, such as reduced carer time, but some show that the drugs do not reduce the risk of institutional care.

Emerging drugs
New drugs are based on firmer knowledge about the disease mechanism, targeting the root cause of brain degeneration rather than symptoms, but take 15-20 years to develop. There are around 640 drugs under various stages of development for neurodegenerative disorders. A handful of these target Alzheimer’s disease. Possible targets include ‘amyloid plaques’ and ‘protein-tangles’ (Box 1). Drugs targeting such features are in late stages of clinical development, with some results expected in 2007 or 2008. A ‘vaccine’ is also under development, and other drugs highlighted in population studies may also prove beneficial.

Response to NICE recommendations
A number of bodies appealed against the 2006 appraisal, feeling that it was not transparent enough, and did not place sufficient value on wider benefits of using the drugs. There was criticism for not factoring in:

- reduced carer time;
- reduced prescription of other drugs (neuroleptics);
- wider health service costs;
- cumulative benefits of early diagnosis/treatment;
- reduced overall treatment costs due to only ~40% of patients responding to treatment.

The appeal was not upheld. Underlying much of the appeal process was whether a measure like the QALY could adequately capture the complex benefits of the subtle cognitive improvements seen with these drugs. Broader measures that might address this in future, are being developed. The Royal College of Psychiatrists has criticised the guidance suggesting it will discourage early-

diagnosis, and noting that the test used to categorise patients is culturally and educationally biased and, thus, an inadequate sole guide for treatment.

Funding provision of long-term care
Reviews of the current system for carer funding highlight its ambiguity and unfairness for dementia sufferers. A Commons Health Select Committee report, drew attention to the partition between health (free at the point of delivery) and social care (means-tested). This has led to two parallel streams for funding care (Box 5), and raises a number of issues concerning the fairness of eligibility criteria for dementia sufferers. First, there is confusion over exactly who is eligible for which stream as there is significant overlap between the criteria. Similar language is used, for example, in the criteria for the top-tier of Registered Nursing Care Contribution (RNCC) in England, and for Continuing Care (NHS CC) (Box 5). In practice, the system discriminates against dementia sufferers as it tends to place them in the RNCC stream compared with, say, terminal cancer patients, who are more likely to have costs met by the NHS CC stream. Second, there is considerable variation in the way that the criteria are applied by different Strategic Health Authorities, and the Health Ombudsman has highlighted that many have been unlawfully denied funding. Often, funding can fluctuate as the disease progresses, which can be distressing and disruptive for carers and sufferers.

In contrast, Scotland provides free personal and nursing care at a cost of ~£140 million (0.2% Scottish GDP). Reviews of this system by the Scottish Executive Health Committee and others, highlight free personal care as having made provision for those with dementia more equitable. A similar move in England & Wales would cost ~£1.75 billion, but would have to be considered in the context of the wider debate on reform of long-term care provision. The Department of Health (DH) is currently devising a ‘national framework’ to clarify some of the confusion over criteria, and is expected to report in 2007. It has no plans to introduce free personal care.

Service provision reform
Service provision for the elderly, particularly dementia sufferers, has been criticised for being non-integrated, and non-informative. The challenge in coming years is delivering the DH’s vision of choice, patient-centred care, carer support, seamless service provision and prevention,
Box 5. Long-term care funding now & in the future. When does the NHS fully pay for long-term care?
The ‘NHS Continuing Care’ (NHS CC) stream meets all personal and nursing costs, as well as housing costs in a
nursing home. Eligibility is assessed by Strategic Health Authorities to comply with the ‘Coughlin Judgement’ and
other case law, where the primary care need is health.

When is care means-tested?
The Registered Nursing Care Contribution (RNCC) is an
assessed tiered (England) or fixed payment (elsewhere in the
UK) by the NHS towards registered nursing-care. Personal
care costs are means-tested, except in Scotland where these
are fully met. An asset threshold in the region of £21,000 is
used, above which a person must pay towards their care.
Housing costs associated with care homes are means-tested.

How should long-term care be funded in the future?
Opinions differ but key factors are affordability, sustainability and fairness. The Royal Commission suggested free
personal care, implemented in Scotland. The Wanless
Social Care Review suggested a non means-tested ‘Partner-
ship model’, with the state contributing 66%, and the rest
met equally by the individual and the state. The Joseph
Rowntree Foundation suggested a number of improvements,
including reform of the current benefits system.

How much is it going to cost in the future?
Projections suggest that demographic pressures mean
spending on care would need to increase from 0.96% GDP
(2002) to 1.96% GDP in 2051. Free nursing care would
change this from 1.18% (2002) to 2.40% GDP in 2051.

on the ground. An important issue is how best to
integrate health and social services. Options here include
greater support for multidisciplinary health and social
care teams, providing locally pooled budgets, and a
'Single Assessment Process', to ensure person-centred
care across agencies.

One important role, recognised by the DH, NICE and the
Scottish Intercollegiate Guidelines Network, is that of
'memory assessment centres'. The hope is that these will
aid early diagnosis, prescribe interventions and advice,
signpost services, and be the focus of integrated teams.
However, the centres are not usually community-based,
and may be less viable in the wake of the NICE drugs
appraisal. Another issue is the lack of 'descriptive'
population data (how do sufferers currently access
services, and what outcomes work best?) which are
needed to address effective service provision. Given that
dementia is a major factor in service demand (~30% of
occupants of hospital beds over 65 years of age, and
~62-74% of residents in care institutions suffer from
dementia), greater emphasis on training of health and
social care professionals is another important issue.

Research financing & infrastructure
Public and charitable expenditure on Alzheimer’s disease
research in 1999 was £5.5 million and the figure spent
by the pharmaceutical industry is likely to be many times
more than this. The DH has set up a UK Clinical
Research Network specifically for dementia and other
neurodegenerative disorders, to aid the conduct of
clinical trials. The EU allocated €40 million to support
funding into Alzheimer’s in the FP6 programme, which
supports collaborative research in the Union. In contrast,
the US National Institute of Health spent $656 million
on Alzheimer’s disease research in 2005. A recent House
of Lords report15, highlighted the need for a better
strategy for UK research into ageing, including dementia.
Recommendations included a dedicated strategic body,
and specialised fellowships/career development awards.
Also highlighted was the need for infrastructure support
for more population studies. These would be needed in
future to address the question of whether the UK’s
population will be at increased risk on account of
increasing rates of obesity, high blood pressure, and
heart disease rates (Box 1).

Overview
- Numbers of people affected by dementia are set to
increase from 750,000 to 1.3 million in 2031.
- The economic costs of dementia are thought to be in
the region of ~£7 to £15 billion.
- Clearer biological targets for treatment have been
identified, and new drugs are likely in 5-10 years.
- The current system for funding long-term care is
seen as inequitable for dementia patients.
- There is scope for a more integrated approach to
service provision for dementia patients.

Endnotes
1 Government Actuary Department & Office of National Statistics,
Series PP2 No 25 2006
5 Lowin A et al, International Journal of Geriatric Psychiatry
16:1143-1148 (2001)
6 National Audit Office and PSSRU report new figures later this year.
7 House of Commons, Report of the Health Select Committee, Session
2004-05 HC 399-I
8 The Health Service Ombudsman, Session 2002-03 HC 399 & Session
2004-05 HC 144
9 Bell D et al, Financial care models in Scotland and the UK, Joseph
10 The Audit Commission. Forget Me Not: Mental Health Services for
13 Department of Health. Cm 6737, January 2006
14 Royal College of Psychiatrists, Who care wins. 2005
15House of Lords, Report of the Select Committee on Science &
Technology, Session 2005-06, HL Paper 20-I