Commentary on

Living Well with Dementia: A National Dementia Strategy

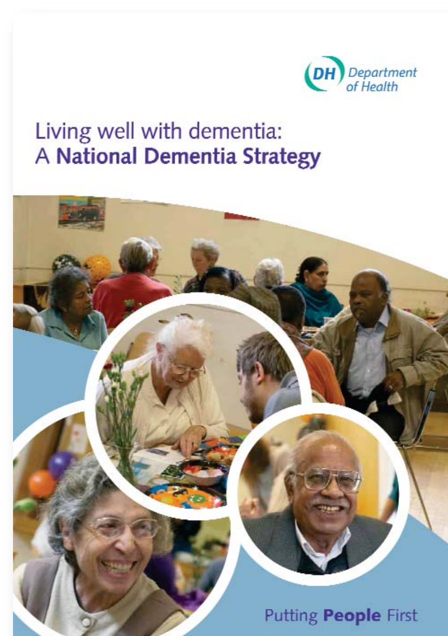
Dr Andrew J Larner
is the editor of our Book Review Section. He is a Consultant Neurologist at the Walton Centre for Neurology and Neurosurgery in Liverpool, with a particular interest in dementia and cognitive disorders. He is also an Honorary Apothecaries' Lecturer in the History of Medicine at the University of Liverpool.

Correspondence to:
AJ Larner,
Walton Centre for Neurology and Neurosurgery,
Lower Lane, Fazakerley,
Liverpool, L9 7LJ, UK.
E. a.larner@thewaltoncentre.nhs.uk

Who can legislate for snow? After months of waiting, a (or is it "the"?) National Dementia Strategy (NDS)[1] was officially launched on 3rd February, 2009 (this was originally planned for October, 2008), but its media impact was somewhat diluted by the obsession with snowfall and the resultant school closures and cancellation of London's buses. Brief items appeared on BBC News, but nothing in the next day's *Guardian*.

The NDS builds on a consultation document[2] issued by the Department of Health in June 2008. Both propose three key themes to address the problem of dementia: improved awareness, early diagnosis and intervention, and a higher quality of care. There are 17 "key objectives", but many of these fall outwith the clinical domain, such as an information campaign to raise awareness and reduce stigma, improving community personal support services, housing support and care homes. Perhaps consistent with this is the fact that hospital clinicians without managerial roles are conspicuously absent from the NDS target audience (p2). Moreover, the NDS is explicitly not detailed clinical guidance, since the NICE/SCIE guidelines of 2006 are said to fulfil that role (p15), a document which has previously been commented upon in these pages.[3] There is, however, a proposed care pathway for the implementation of the strategy (p22), although specified roles for specified specialists at specified times are not suggested (cf. ref 4).

For clinicians, the key chapter will be that devoted to early diagnosis, and particularly objective 2, "good quality early diagnosis and intervention for all" (p33). This is to be delivered by "commissioning of a good quality service, available locally, for early diagnosis and intervention in dementia, which has the capacity to assess all new cases occurring in that area". According to the NDS, diagnosis should be carried out by "a clinician with specialist skills" (p35), and this will require the commissioning of a specific service for early diagnosis and intervention (p36), rather than utilising existing services. This is because old age psychiatry services are said to be focused on the severe and complex end of the spectrum leaving early diagnosis unaddressed, whilst geriatricians and neurologists are "saturated at present with their current work with those referred to them with dementia and complex physical co-morbidity and younger and atypical presentations respectively" (p36). The proposed new service would focus solely on early diagnosis and intervention and would be complementary to the work of old age psychiatry, geriatrics, neurology and primary care (p37). This new service, the applicability of which is based on the Department of Health pilot study in the Croydon Memory Service,[5] "might be provided by any of a number of types of specialist with diagnostic skills in dementia (e.g. old age psychiatrists, geriatricians, neurologists, or GPs with a specialist interest) or combinations thereof". It will be based on "local decisions … based on existing service provision and where local skills and enthusiasm lie". There is no expectation that all areas will implement the strategy within 5 years (p13).



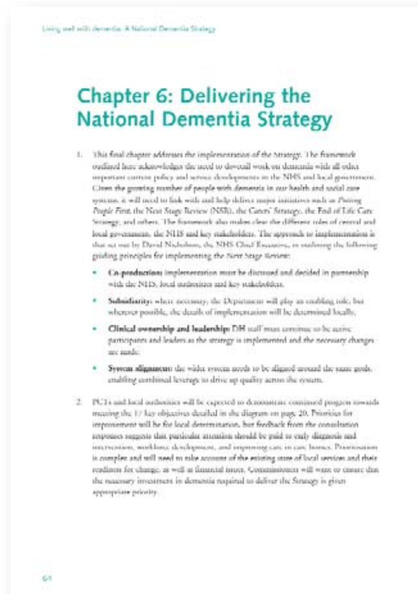
Whilst the NDS goals are self-evidently laudable, the pragmatics are that everything seems to hinge on commissioning, to which end something called "World Class Commissioning" guidance for dementia will operate (an 18-page Annex is devoted to this creation). Nonetheless, one suspects that there will be differences of interpretation and hence different service models emerging in different areas, dependent upon the views of individual managers. As an example, one NDS objective is the appointment of "demen-

tia advisers" to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers (p11). About 2 years ago we proposed a similar post of "dementia care manager" be set up at this centre to coordinate referrals between our diagnostic service and social care services, but this was summarily rejected.

Sceptic that I am, I find the idea of a new service devoted to early diagnosis a little perplexing. Isn't this just an extension of existing services, the more so if it is to be provided by those with specialist skills (e.g. old age psychiatrists, geriatricians, neurologists) already providing the existing service? The approach of extending existing services is apparently good enough in other circumstances: on the issue of inappropriate use of antipsychotic drugs in patients with dementia, it is suggested that "commissioning an extension of the existing role of the old age community mental health teams … rather than … setting up a separate service" would be appropriate (p60). There also seems to be an expectation that early diagnosis of dementia is always a straightforward matter, whereas empirically it is often difficult, requiring patient follow-up and reassessment over time. There is, as far as I can see, no explicit acknowledgement that dementia is aetiologically a heterogeneous syndrome, which may require rather different diagnostic skills and interventions dependent upon cause.

Furthermore, what case mix would an early diagnosis service see? I think many of its clients would be the "worried well", those with self-reported and physiological memory lapses, rather than those with pathological neurodegeneration. Would such a service be able to deal with these issues, or would there be a need for onward referral for assessment of the non-demented? Top-down policies may have consequences contrary to those expected, for example, despite the expectation in some quarters that NICE/SCIE guidelines would make a neurology-led cognitive clinic redundant, such that managers mooted its closure, referral numbers have in fact increased significantly.[6]

> *Formulation of policy (top-down) is relatively easy, whereas implementation (bottom-up) is rather more difficult*


Living well with dementia: A National Dementia Strategy

Chapter 6: Delivering the National Dementia Strategy

- **Co-production:**
- **Subsidiarity:**
- **Clinical ownership and leadership:**
- **System alignment:**

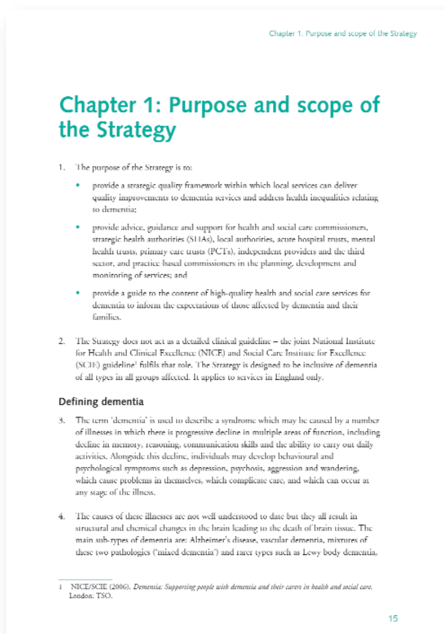
64

NDS is a five-year plan (a name which will inevitably, for the historically minded, conjure visions of Stalin), and seems to be one part of a unified plan, if not for the whole of society then for much of the care sector, since it is proposed to dovetail with the Carers' Strategy, the National End of Life Care Strategy, NHS Next Stage Review, *Putting People First*, and possibly others (p64). Whilst integration is of course desirable, policy does not appear to be entirely joined up, since early intervention will not, of course, include cholinesterase inhibitors if the NICE 2006 cholinesterase inhibitor guidance is followed.

Formulation of policy (top-down) is relatively easy, whereas implementation (bottom-up) is rather more difficult. Only time will tell whether this policy can be meaningfully delivered. ◆

REFERENCES

1. *Living well with dementia: a National Dementia Strategy.* London: Department of Health, 2009.
2. *Transforming the quality of dementia care: consultation on a National Dementia Strategy.* London: Department of Health, 2008.
3. Doran M, Larner AJ. *NICE/SCIE dementia guidance: time to reconsider.* Advances in Clinical Neuroscience & Rehabilitation 2008;8(1):34-35.
4. Larner AJ. *Integrated care pathways in dementia: challenge to National Institute for Health and Clinical Excellence/Social Care Institute for Excellence guidance.* J Integrated Care Pathways 2007;11:95-99.
5. Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J. *Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model.* Int J Geriatr Psychiatry 2007;22:782-788.
6. Larner AJ. *Impact of NICE/SCIE dementia guidelines in a neurology-led memory clinic.* Clin Med 2009;9:in press


Chapter 1. Purpose and scope of the Strategy

Chapter 1: Purpose and scope of the Strategy

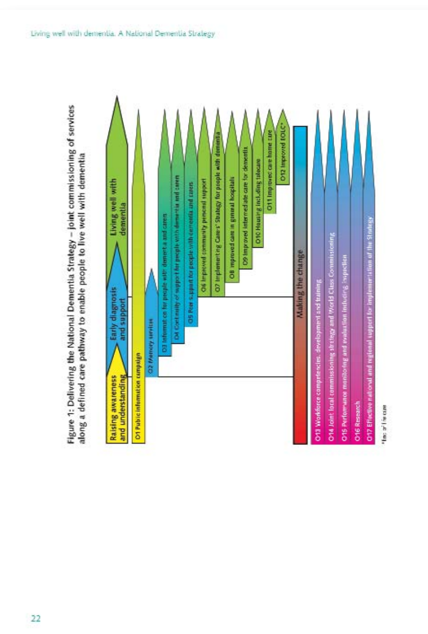
1. The purpose of the Strategy is to:
   - provide a strategic quality framework within which local services can deliver quality improvements to dementia services and address health inequalities relating to dementia;
   - provide advice, guidance and support for health and social care commissioners, strategic health authorities (SHAs), local authorities, acute hospital trusts, mental health trusts, primary care trusts (PCTs), independent providers and the third sector, and practice-based commissioners in the planning, development and monitoring of services; and
   - provide a guide to the content of high-quality health and social care services for dementia to inform the expectations of those affected by dementia and their families.
2. The Strategy does not act as a detailed clinical guideline – the joint National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE) guideline[1] fulfils that role. The Strategy is designed to be inclusive of dementia of all types in all groups affected. It applies to services in England only.

Defining dementia

3. 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 function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.
4. The causes of these illnesses are not well understood to date but they all result in structural and chemical changes in the brain leading to the death of brain tissue. The main sub-types of dementia are: Alzheimer's disease, vascular dementia, mixtures of these two pathologies ('mixed dementia') and rarer types such as Lewy body dementia,

1 NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care.* London: TSO.

15



Chapter 4. Early diagnosis and support

Good-quality early diagnosis and intervention for all

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

How this can be delivered

- The commissioning of a good-quality service, available locally, for early diagnosis and intervention in dementia, which has the capacity to assess all new cases occurring in that area.

The case for change

Under-diagnosis is the current norm

1. Currently only about one-third of people with dementia receive a formal diagnosis at any time in their illness.[17] 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. A core aim of the National Dementia Strategy is therefore to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis. There is evidence that such services are cost effective, but will require extra initial local investment to be established. When established, such services can release substantial funds back into health and social care systems.[18]
2. In its Operating Framework for 2008/9,[19] the Department of Health summarised the situation as follows:

   > *"…providing people with dementia and their carers the best life possible is a growing challenge, and is one that is becoming increasingly costly for the NHS. Research shows that early intervention in cases of dementia is cost-effective and can improve quality of life for people with dementia and their families…"*

17 NAO (2007). *Improving services and support for people with dementia.* London: TSO.
18 Ibid.
19 DH (2007). *The NHS in England: the Operating Framework for 2008/09.* London: DH.

33