

Dementia: still muddling along?

GPs need more guidelines like fish need more bicycles. Guideline production has become something of a growth industry, and sifting through the output from professional bodies, special interest groups, and regulators like the National Institute for Health and Clinical Excellence (NICE) to make sense of their advice is a huge task. Paying too much attention to guidelines may not be worthwhile, partly because all too often they overvalue professional judgements in the weighting of evidence, and partly because they have remarkably little impact on practice. So the new guidelines on dementia care,¹ jointly produced at the end of 2006 by NICE and its sister organisation the Social Care Institute of Excellence (SCIE), may well be left on the shelf and forgotten. Most GPs will do this, and probably no great harm will come to them and their patients as a result. Many may correctly note the lack of robust evidence of effectiveness for many aspects of treatment and support in dementia care, and opt to muddle along as normal, unimpressed by the attention given to NICE's output by other European health services.² However, some practitioners will need to pay attention to the recommendations, for four reasons.

The first is that the incidence and prevalence of dementia syndromes appear to be increasing. In the 1990s it was estimated that a GP in the UK with a typical list-size could expect a caseload of 10 and an incidence of 1.6 new patients with dementia per year.³ Given the ageing of the European population,⁴⁻⁶ the incidence of dementia at the beginning of the 21st century is likely to be 10 new cases per 1000 people per year. The human suffering that neurodegenerative diseases carry with them is difficult to quantify, but with progressive disorders that can evolve over a decade it is likely to be huge. The economic cost is somewhat easier to calculate. In 1998 the estimated annual cost of dementia in the UK was £5.5 billion, of which three-fifths were borne by patients, carers, and social security funds, one-fifth by social services, and one-fifth by the health service.⁶ Current demographic changes mean that this figure is likely to be an underestimate.

The second reason is that the early recognition of dementia has risen up the policy agenda across Europe,⁷ despite concerns about pathologising individuals and developing expectations that cannot be met.⁸ Dementia has entered the realm of performance management in British general practice, with two elements of dementia care lodged in the Quality and Outcomes Framework (QOF) already, and no doubt more to come. The guidelines' recommendations make ideal elements for the future evolution of QOF. Overall, this is likely to be beneficial for people with dementia, because there is ample evidence of under-recognition of and under-response to dementia syndromes in primary care,^{9,10} although at first GPs may not like the extra workload. Substantial benefits can flow from small efforts, as medical and psychosocial support improves morale, particularly among carers, and reduces the significant psychological distress that people with dementia and their close supporters so often experience.¹¹

If QOF evolves to implement the guidelines using performance incentives, GPs will need to become concordant with the guidelines on the diagnostic work-up of dementia syndromes, where the evidence of effectiveness is reasonably robust that an informant history, use of a simple cognitive function tool, and a small battery of blood tests are helpful.¹² They will also need to demonstrate systematic and structured follow-up that includes ways of 'breaking bad news',¹³ working knowledge of the Mental Capacity Act 2005 and its rules for assessment of capacity to make specific decisions, some skills in coping with psychological and behavioural changes in the mid-stages of dementia,¹⁴ and the ability to support carers in simple but effective ways, without being helped by a deep evidence base. Here some educational input to primary care from old-age psychiatry, mental health nursing or social work may be necessary, a task required of specialists by the National Service Framework for Older People.¹⁵ The Alzheimer's Society also offers a training manual, *Dementia in the community:*

management strategies for primary care, designed for general practice.¹⁶

Surprisingly, given the media controversy, the easiest aspect of the guidelines to implement is drug therapy, where the limited but still useful benefits of the cholinesterase inhibitors are clear from trials¹⁷ and prescription is sanctioned by NICE (except for memantine). The benefits of cholinesterase inhibitors are experienced by a (largish) minority of those who try them, and are less to do with improved memory than with restored social interactions. People with dementia may regain the ability to take part in social activities and relationships once more, and outcome measures may be simple ones of enjoying the company of friends and family, a drink in the pub, or a shopping trip, without experiencing anxiety or expressing distress through disturbed behaviour. GPs may be better placed than specialists to understand how important such gains really are, both to people with dementia and their families.

While all this effort may sound daunting, it is well within the boundaries of generalism¹⁸ and the core skills required are already present in the discipline.¹⁹ The construction of meanings, dialogue about explanatory models of illness and the search for shared understanding that are necessary in dementia care are also part of the expertise of general practice.²⁰ GPs are highly regarded by families of people with dementia because they provide continuity of care across the whole trajectory of the disease, have established relationships of trust, act as advocates and problem-solvers when other agencies fail to do so, and open the gate to other sources of help.²¹ The presence of support has a positive effect on carer mood and quality of life, even if that support is not taken up.

The third reason for taking note of these guidelines is that public expectations about dementia and the treatments for it are changing, which will have a direct effect on workload in general practice and on demand for specialist services. The 'Alzheimerisation' of old age^{22,23} is underway, so that many older people now understand memory problems as

a possible sign of an emerging dementia syndrome. While many will not want to pursue this unhappy idea, some will, and they will be able to draw on the information resources of the voluntary sector and NICE itself to understand what they should receive, in terms of assessment, and what the treatment options may be, in terms of medication and psychosocial support. 'Demand push' is going to rise and enter the consulting room more often because in most places specialist services will not be able to cope with it. GPs attending to their own ageing parents or grandparents, are also unlikely to accept poor quality care and will therefore contribute to this 'demand push'. Inspectors and regulators of health and social care services will be increasingly interested in the views of family members about how services are measuring up to the guidelines' benchmarks, so the temptation to fend off public demand by categorising dementia as a specialist problem outside the generalist job description may not work for long.²⁴

The fourth reason that GPs need to pay attention to the dementia care guidelines is that guidance about new technologies and medications has to be implemented by the NHS, while other recommendations become benchmarks for inspectors and auditors. The political campaign around the supposed withdrawal of the cholinesterase inhibitors and the actual withdrawal of memantine from NHS formularies has clouded the impact of the NICE recommendations on medication use. The guidelines state that cholinesterase inhibitors can only be prescribed to people with moderate to severe dementia, but the definition of moderate is to be a clinical one, hinging on evidence of 'significant impairment'. Since there is no requirement to stop treatment if there is no evidence of benefit — a logical approach in a progressive degenerative disorder where 'benefit' is hard to conceptualise, let alone gauge — the numbers of patients taking these drugs may well increase, with a significant impact on prescribing budgets. At the same time the recommendations that all areas should have memory assessment services, and that neuroimaging (preferably by MRI scanning) to diagnose and then sub-type dementia should become a normal component of the clinical work up,²⁵ will stretch primary care trust funds just as they are struggling to break even, let alone produce a surplus. Add to this the potential crisis in care-home

capacity, as the number of homes decreases and the demand rises,²⁶ and the task of commissioning begins to look formidable. GPs involved in commissioning will need to consider how they can expand services for people with suspected dementia, while balancing the books.

One of the debates in the NICE guidelines development group was about training all relevant disciplines, from general practice to social care, in the use of the guidelines, an idea that was resisted on the grounds that selective reading of them would be much more productive. While most GPs need only register the existence of the dementia guidelines, their forward-thinking practice managers will be future-proofing themselves against QOF's evolution by thinking about how to demonstrate concordance with the auditable clinical components. The guidelines may alert us to the implications of the Mental Capacity Act 2005 in England and Wales (which will be fully implemented in September 2007), since there is likely to be interest around advance planning of end-of-life care and treatment in conditions where capacity to make decisions decreases. Commissioning leads will look closely at the cost models that accompany the guidelines, while trainers will extract lessons for their registrars. GPs with care-home patients who have dementia will dip deeper into the 474 pages of the full guidelines and the growing number of those with special interests in old-age psychiatry or primary care of older people will read every chapter. Therapeutic nihilists may still ask if there is any point in even thinking about a condition for which, in their view, nothing can be done,²⁷ but their time is passing.

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