

Dementia, screening, targets, and incentives:

Primum non nocere

Dementia is in the news, repeatedly. That is positive. Media attention has raised awareness of the disorder and much good has resulted, such as 'Dementia Friends' (<https://www.dementiafriends.org.uk/>), and other initiatives.¹ However, some government proposals are controversial, including screening, setting targets for identifying dementia, and NHS England's Enhanced Service Specification Dementia Identification Scheme.²

PRIMUM NON NOCERE — FIRST DO NO HARM

Target driven 'overdiagnosis' can be harmful. This is likely to be more problematic in localities where hypothesised targets are set too high. Some doctors have encountered situations of having to 'un-diagnose'³ patients wrongly labelled as having dementia. Since dementia is said to be the most feared illness in people aged over 55, living with a wrong diagnosis can cause unnecessary emotional suffering, sometimes for years. It has other health disadvantages, linked to failing to diagnose alternative treatable mental disorders or the tendency of hospital staff to pay less attention to physical disorders in people labelled with dementia; both scenarios have potentially disastrous consequences. It can also cause social disadvantage, such as unnecessarily relinquishing a driving licence. To encourage targets to be met in England, locality data are displayed on a name-and-shame 'dementia map'.⁴ Department of Health directives are well motivated in promoting dementia identification with the objective that more people will receive appropriate treatment and care. However, this potentially valuable objective fails to consider that specialist expertise is consumed by routine diagnostic work, which, together with concerns about funding NHS memory services, voluntary services and older people's social care,⁵ contributes to undermining the support that can be given.

Another strategy, dementia screening or active 'case-finding' in primary care, proposed in 2012, remains contentious. The UK National Screening Committee made a clear statement on dementia in January 2015: 'Systematic population screening programme not recommended.' Of every 100 people aged >65 years screened for dementia with conventional tests, 18 would

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have a positive result of whom 12 would not have dementia.⁶ Opportunistic screening when attending the GP with other disorders, rather than being invited for screening, has been especially criticised since fear of being found to have dementia could discourage patients from attending their GPs for other disorders.⁷

In 2014, the Dementia Identification Scheme offered GPs £55 for each person with a dementia identification. This has been popularly interpreted as £55 for each dementia diagnosis. However, 'identification' and 'diagnosis' are not synonymous. The singular noun 'dementia' (the identification) is not a single condition but an umbrella term for multiple diagnoses. It is used in a similar way to 'cancer'. One would not diagnose 'cancer' generically, and we should resist the temptation to label people with 'dementia' in place of making a specific diagnosis. This is important because different dementias vary in their prognosis, course, prominent challenging symptoms and treatment, and patients and their carers often benefit from specific guidance.

DEMENZA: IDENTIFICATION AND DIAGNOSIS

Various factors influence the identification and diagnostic process. Ongoing stigma, lack of patient awareness of their own symptoms, labelling their forgetfulness as 'ageing' rather than illness, and spouses' dedication to supporting each other without seeking help could all prevent presentation to the GP. Educating people about dementia may help, but some may not want to know the diagnosis. In this context, incentivised diagnosis may not be ethical.

NHS England's National Clinical Director for Dementia, Alistair Burns's 'Dementia narrative' published in the Dementia Identification Scheme provides a helpful diagnostic pathway. Diagnosis is a two-stage process. First, differentiating it from changes in memory expected as part of normal ageing and from other disorders indicated in the '5Ds': Dementia, Delirium, Depression, Drug effects, and Diagnoses (other). Second, to determine the type of dementia, the commonest of which are Alzheimer's, vascular, and Lewy body. Both stages require a comprehensive assessment including a history, collateral information from someone who knows the patient well, a physical and mental state examination, and selected ancillary investigations. Brain scanning is not always needed. Considering common differential diagnoses is crucial: media prominence of dementia risks lowering awareness of the range of common psychiatric conditions of older people. A high index of clinical suspicion is needed to avoid accepting dementia as a catch-all, thus missing treatable, reversible disorders.

NHS England's 2015 short guide for GPs, *Dementia Diagnosis and Management*, is highly recommended; it is the best I have read so far.⁸

THE TOOLS AVAILABLE

Brief screening assessments are important, including questions of function as identified by Creavin *et al* in this issue.⁹ A diagnostic criterion for dementia is that impairment affects daily life. Asking about tasks salient for the patient and their family may help clarify significant cognitive impairment. This should be done in conjunction with using a

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formal brief cognitive screening tool. Various cognitive screening tools are available. They all have pros and cons: the 'best' is probably that which the GP feels most comfortable and confident to use. The clue to getting the most out of a brief cognitive screening tool is to write down the wrong answers: for example, if the person is asked to state the year, 2014 and 1946 are both wrong, but qualitatively the answers have different implications. The Mini-Mental State Examination (MMSE) is no longer recommended for screening since copyright regulations mean that the owners have the right to charge for its use. The General Practitioner Assessment of Cognition (GPCOG),¹⁰ which includes, where possible, information from an informant, seems particularly apposite. Like Creavin *et al*,⁹ the GPCOG emphasises function. Another diagnostic clue commonly missed in clinical practice is the importance of obtaining a detailed history over at least a year to profile the changes in cognition and function: a rapid loss of cognition or the presence of confused behaviour, for example, wandering at night during the previous few hours, days, or weeks is more likely delirium than dementia. In addition, a patient who is excessively preoccupied with their memory loss should prompt consideration of depressive illness.

GPS AND THE MENTAL HEALTH OF OLDER PEOPLE: OUR LEGACY

During the 1980s, articles in this journal and others rarely showed enthusiasm about older people with mental illness, and in 1987, the RCGP Occasional Paper, *Preventive Care of the Elderly*,¹¹ overlooked their mental health. This suggests that GPs lacked awareness (or perhaps interest?) about the implications of older people's mental illnesses, including dementia, as major health issues.

In 1996, the acetyl-cholinesterase inhibitor (AChEI) donepezil (Aricept® Eisai) was marketed for Alzheimer's disease. To over, or inappropriately, prescribe a mild palliative treatment for a common long-term condition, at almost £1000 a year per person, was potentially prohibitive. Those of us working in the field at the time

understood that the unwritten reason why the National Institute for Health and Care Excellence (NICE) recommended specialists to initiate prescribing of AChEIs was to ensure rationing of the drugs. The rationing argument was not politically correct compared to a clinical alternative; that the drugs had to be prescribed by specialists due to their complexity. Thus a myth arose that AChEIs fulfilled this other criterion.

The patent on donepezil expired in 2010; it now costs pennies not pounds so the rationing argument is less strong. Combined with the earlier overlooking of psychiatric disorders in older people, NICE's guidance contributed to undermining skills in primary care for diagnosing, treating, and managing the disorders with a consequent over reliance on secondary services.

INTO THE FUTURE

Memory clinics should not have a monopoly on diagnosis. We need a shift towards diagnosis in primary care, starting by focusing on accurate diagnosis of common disorders with typical presentations, especially Alzheimer's disease, in much older people. Atypical signs and symptoms, which may signify other conditions, or the presence of problematic behavioural symptoms, would prompt referral to specialist services.

Primary care often has nurse-run diabetes or asthma clinics: why not also, with adequate training, clinics for dementia? Diagnosis could then go hand in hand with offering support, directly by the primary care team and through 'signposting' to other agencies, aiming to maintain the patient's and the carer's wellbeing. Secondary services should support the primary care team especially with patients with the most complex conditions. Satellite specialist memory clinics can take place in GPs' surgeries, seeing patients and contributing to staff education, a model already in practice in some localities.¹² These goals are achievable and are likely to be in the best interests of patients and their families.

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