

# Dementia

## BULLETIN



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## Exploring and explaining shared-care protocols

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“The aim is to enable patients to maintain optimum levels of independence, functioning and quality of life”

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The Department of Health (DoH) has highlighted the significant role to be played by primary care services in the diagnosis, treatment and care of people with dementia.<sup>1</sup> In order to achieve this aim, the *National Service Framework (NSF) for Older People* has sought to raise the profile of mental health problems in older age and has tasked Primary Care Trusts (PCTs) to ensure that every GP practice has in place a protocol, agreed with local specialist services, for the management of dementia.

Such shared-care protocols are supported by the DoH as mechanisms that should aim to:

- Promote inter-agency communication
- Support community care
- Define access routes to – and involvement of – specialist mental health services.

In the context of dementia, the aim is to enable patients to maintain optimum levels of independence, functioning and quality of life, for as long as possible, taking into account the specific needs of that individual and their family or carers.

PCTs are tasked with fitting together the needs of the patients and of primary and secondary care in developing shared-care protocols



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*‘ A shared-care protocol reflects a joint process developed between primary and secondary care ’*

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Such an aim reflects a growing awareness that services must become more person-centred in their approach; it is clear that promoting a care pathway through a shared-care protocol is of benefit to the wellbeing of people with dementia, and their carers. With this in mind PCTs were set the target of realising their introduction by April 2004.<sup>1</sup>

### **What exactly are shared-care protocols?**

The management of many chronic health problems does not occur exclusively within primary or secondary care. In reality, boundaries are much less clear than they used to be. There is a political agenda for services to be more accessible to the consumer and, so, previously hospital-based interventions have moved out into local surgeries. GPs have been encouraged to specialise and, consequently, an overlap between the two services has developed.

Despite this, there remains a considerable population of people with chronic health problems whose needs are best met by a collaboration or partnership between hospital specialist and general practitioner. In order to achieve such a collaboration, it is recognised that there needs to be a clear understanding of the purpose and responsibilities of each partner and the shared-care protocol should act as the framework for this.

Protocols are written plans that specify a procedure to be followed for the care of a particular condition.<sup>2</sup> A shared-care protocol reflects a joint process developed and agreed between primary and secondary care. In the case of dementia the shared-care protocol would aim to specify the responsibilities, and best practice, in relation to:

- Referral
- Assessment
- Diagnosis
- Treatment
- Monitoring
- Carer support.

#### ***GP responsibilities***

Responsibilities of the GP include, most importantly, early identification of patients with possible dementia and prompt referral to suitable specialist

services. Early referral, as a means of preventing or reducing crisis, has many benefits, for patient and health service alike. These include allowing early treatment to be initiated, and delaying admission to an institution. It may also allow patients and their families a period of time to come to terms with the diagnosis and to plan to adjust their lives to minimise the impact of the disease.

#### ***Hospital specialist responsibilities***

Where referral is made, the hospital specialist carries responsibility for the prompt assessment of the patient, confirmation of the diagnosis and the development of an appropriate management plan. This plan will focus on pharmacological intervention and there is, therefore, a further responsibility on the part of the hospital specialist to identify those people with dementia for whom drug treatment may be suitable. The responsibility also extends (under current guidance) to: initiation of treatment; dose titration; prescription of treatment for the first three months; ongoing monitoring; and advising on continuation or stopping of treatment according to progress.

The management plan should also consider non-pharmacological treatment through psychosocial interventions: through the counselling of people with dementia – along with their families and carers – regarding the likely progress of the disease; and through the provision of information and access to appropriate support services.

### **Why are shared-care protocols needed?**

Historically, health and social services have been focused around a service model that responds to the later stages of dementia when carers are struggling to cope with the demands placed upon them. Such service provision has led to a culture that promotes both late diagnosis and, inevitably, a crisis intervention being required; but this fails to place any emphasis upon the early lived experience that individual people with dementia go through. It is now recognised that most care provided by hospital-based services has been tainted by a malignant social psychology,<sup>3</sup> meaning that we are still

failing to meet the needs of extremely frail and vulnerable people.

Primary care services have equally failed. The *Forget Me Not* report<sup>4</sup> criticised GPs for, at best variable, at worst nihilistic practices regarding older people with mental health problems. The report found that, of those GPs included:

- Two-fifths were reluctant to diagnose dementia at an early stage
- Most did not use a protocol to aid the diagnosis of dementia
- A quarter felt they did not have access to specialist services
- More than half had received inadequate training for dementia recognition or management.

In the context of such findings the DoH's emphasis on family doctors taking a significant role in dementia management may call for a seismic shift in attitudes, rather than simply a new direction in clinical responsibility.

Despite the laudable endeavours of many clinicians, there is still a pressing need to improve the quality of services for people with dementia and the support that they and their families receive. Shared-care protocols may play some part in this as not only do they highlight a collaboration between services who have the necessary skills to meet the individual's needs but they also place emphasis upon the pursuit and application of best practice.

Additionally, shared-care protocols have other benefits, all of which sit comfortably with the person-centred agenda of the 'new culture of dementia care'.<sup>3</sup> The benefits of shared-care protocols include:

- Stressing the importance of early diagnosis
- Emphasising the need for proper diagnosis, treatment and monitoring
- Emphasising the importance of the individual and the involvement of their family
- Providing a clear guide to patients and families of what to expect from services
- Helping professionals to map services and service provision
- Promoting the benefits of good practice throughout the life of the patient.<sup>5</sup>

It is also important to have a means of grounding policy changes, guidelines and philosophical principles into the reality of clinical services that are managing

dementia in a holistic and integrated way.<sup>5</sup> Well-drafted, mutually agreed and adequately resourced shared-care protocols may be able to offer this.

## What could be the potential drawbacks?

Collaboration between primary and secondary care does not automatically mean that improvements will occur. A recent systematic review questioned whether GP involvement with specialist teams improved patient outcomes and found no consistent benefit in cases of most chronic conditions, and only a modest benefit in some chronic mental health conditions.<sup>6</sup>

The mere fact that shared-care protocols exist does not necessarily mean that they will be used – particularly if attitudes towards dementia remain negative. Inertia will be fuelled by the limited financial incentive for busy GPs to take on yet another pseudo-specialist role. In addition, if protocols are developed by commissioners without the active participation of GPs, the sense of ownership will be compromised and the potential for resistance – or simple disinterest – increased.

Overall, there has to be an emphasis on changing GPs' behaviour. In the case of dementia, failure to make early referral is rooted in a number of myths including:

- There is nothing that can be done, so why bother referring?
- The feeling that making too many referrals to secondary care suggests a weakness on the part of the GP and may overwhelm the services available
- Fear of making an inappropriate referral.

These myths emerge because of either ignorance or lack of familiarity with dementia. It is recognised that, with a few notable exceptions, most GPs come into contact with dementia on an irregular basis and that in the year 2000, there was no specialist training or support available to GPs in 40% of geographical areas.<sup>4</sup> Increased familiarity impacts upon behaviour, probably by demolishing some of these myths. The systematic review cited above was subject to a further Cochrane review which commented that all the included studies demonstrated improved clinical behaviour for GPs and that a

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*● Inertia will be fuelled by the limited financial incentive for busy GPs to take on yet another pseudo-specialist role ●*

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formal relationship between generalist and specialist changes the clinical practice of both, probably for the better.<sup>6</sup>

### How much progress has been made so far?

Reporting on progress thus far in respect of the NSF for older people, the DoH states that it simply does not know if targets are being met, as no national measure of performance has yet been undertaken.<sup>7</sup>

What is clear – from evidence available via the internet, conference reports and a small number of published accounts – is that much activity is ongoing to develop shared-care protocols. Despite this, a review of *Standard Seven*, undertaken by the Commission for Health Improvement (CHI) has identified concerns regarding progress and, in particular, states that GP engagement is patchy and that any current protocols for dementia are not being consistently applied.<sup>8</sup>

It is unlikely that the milestone for every GP practice to have a protocol in place, agreed with local specialist services for the management of dementia, will be met. However the DoH seems inclined to adopt a more flexible and sanguine approach and it may be sufficient to have protocols drafted by April 2004 with subsequent negotiation to follow.

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