

Transforming the quality of dementia care: Consultation on a national dementia strategy – June 2008

BSRM RESPONSE – 11 September 2008



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Views are sought on the following:

Chapter 1 – Improved Awareness

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

- a. Although the BSRM supports the outcomes and recommendations we are concerned by the implication throughout the document that dementia is a single entity. On page 29 a campaign is advocated, to communicate the idea that 'dementia is a disease'. The intention here is good, but the message is deeply flawed and will have negative effects, particularly for people who suffer from progressive cognitive impairment as a complication of a primary disease such as multiple sclerosis or Huntington's disease. Dementia is a process, due to a number of different diseases – to call dementia a disease is like calling blindness 'a disease'.
- b. Substantial numbers of people with progressive neurological diseases have progressive cognitive impairment; for example a community survey showed that 46% of those with multiple sclerosis had cognitive impairment, 34% having memory impairment (McIntosh-Michaelis SA et al The prevalence of cognitive impairment in a community survey of multiple sclerosis. Br J Clin Psychol. 1991; 30: 333-48)
- c. All the messages concerning raising awareness of dementia apply to neurological conditions where, paradoxically, the label 'dementia' tends to be used less by both patients and professionals even when cognitive disabilities are severe. It is important to direct professionals towards relevant NICE Guidelines such as those for the Management of Multiple Sclerosis in Primary and Secondary Care, where cognitive management is covered.
- d. Raising public awareness will require a strong conceptual grasp of the medical and social issues producing stigma and disability. We notice that rehabilitation concepts are not well developed in the document, which should have made use of the WHO International Classification of Functioning, Disability and Health (ICF) as a conceptual framework for describing rehabilitation goals.
- e. We strongly support the message that people with dementia 'can continue to make a positive contribution to their communities' (p. 29). However, the document has very little specific content concerning systems to enable people to remain employed in the early stages of dementing process, or concerning the creation of new frameworks for social participation. Raising awareness of people's potential to participate will be worse than useless without infrastructure to enable expectations to be met.
- f. We support the use of the concept of rehabilitation but suggest that awareness-raising must include dissemination of information about specialist resources for rehabilitation, including the expertise of consultants in Rehabilitation Medicine, who spend most of their time working with people who either have severe cognitive impairment or are at future risk of cognitive problems and progressive dementia. They specialise in the needs of younger people and the facilitation of relevant roles such as parenting, education and employment.

2. Is there anything that has been missed to help us improve public and professional awareness of dementia?

- a. As suggested above, the BSRM thinks it is essential that the public and professionals

should be much more aware of the impact of cognitive impairment on people with long-term neurological conditions and their families.

- b. There is a sense in which, broadly speaking, dementing illnesses are long-term neurological conditions. The document failed to make any reference to the National Service Framework for Long-Term Neurological Conditions. The Department of Health intended the lessons of this NSF to be extended to other long-term conditions and they are fully applicable to people with dementia and their families – the BSRM believes that a campaign of awareness-raising should emphasise links with the NSF for LTNC.

3. What can you or your organisation do to help implement the recommendations?

The British Society of Rehabilitation Medicine can play a role in encouraging multidisciplinary rehabilitation teams to work closely with dementia services in educating the public and professionals about cognitive impairment and dementia. We can draw attention to Dementia Strategies via our website, and our regular national and regional educational programmes.

Chapter 2 – Early diagnosis and intervention

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

We support the recommendations.

2. Is there anything that has been missed to help enable early diagnosis and intervention?

As mentioned above, more could and should be done to encourage awareness of cognitive impairment among professionals managing long-term neurological conditions where physical disabilities may seem more immediately apparent.

3. Do you agree that the diagnosis of dementia should be made by a specialist?

The diagnostic assessment of different dementing processes will require different specialist approaches. In patients with dementia due to neurological conditions diagnosis can appropriately be made by a Neurologist or by a Consultant in Rehabilitation Medicine.

4. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to a GP first?

Our clinical practice would tend to favour direct referral, but at the same time we strongly advocate services which reinforce rather than undermine the relationship between the individual and the GP.

5. How would the dementia advisers be able to ensure continuity of care?

We have found that similar models of care have been highly successful in other conditions, for example care advisers can be invaluable support to patients with Parkinson's disease, multiple sclerosis, motor neurone disease and Huntington's disease, all of which can and do cause significant dementia. It will be important not to undermine those specialist condition-specific roles which should continue to provide continuity of care in appropriate situations, backed up by specialist advice from dementia advisers. In primary dementias, dementia advisers could be invaluable as key workers. To promote continuity of care we would strongly recommend that they should be community-orientated rather than hospital-based, doing a lot of home visiting and maintaining strong relationships with other community professionals including social services care managers etc. In Rehabilitation Medicine we have developed locality-based multi-agency communication systems (for example see Ward CD et al Multidisciplinary Approaches in Progressive Neurological Disease: Can we do better? Journal of Neurology Neurosurgery and Psychiatry *Neurology in Practice* Supplement 2003; 74: 8iv-12iv). Such systems would be very applicable in dementia.

6. What can you or your organisation do to help implement the recommendations?

The British Society of Rehabilitation Medicine can promote the development of appropriate care pathways for the early diagnosis and management of dementia, particularly in relation to dementia occurring as part of a neurological condition.

Chapter 3 – High-quality care and support

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

- a. Regarding the improvement of hospital care, reference should be made to both the evidence and the recommendations included in the NSF for Long-Term

Neurological Conditions (Quality Requirement 11).

- b. Within the hospital framework particularly, it would be a mistake for a care pathway to focus exclusively on 'dementia' because very similar care requirements arise in the much larger number of inpatients with acute confusional states.
- c. With regard to the above point, the problem of improving professional competence and quality of services is very broad. The creation of separate clinical areas for such patients will not be practical. A mobile support service may be helpful but evidence for the effectiveness of such a service is weak in one condition where it has been evaluated, stroke. Since policies should apply to all staff coming into contact with patients with either confusion or cognitive impairment, they must apply in some degree to an acute medical service as a whole, rather than to a specialised area.
- d. We fully support the recommendation that rehabilitation must be provided appropriately following admission and that people with dementia should not be excluded from services such as intermediate care.
- e. The proposed outcomes for home support are all appropriate. From our experience of working with community-dwelling people with complex impairments and cognitive and behavioural disturbance, we suggest that the involvement of a trained social worker in a care management role will be a very important component in a successful service.
- f. We wholeheartedly support the recommendation for improved registration and inspection of care homes.

2. Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?

No

3. What more could be done in acute care, home care and care homes?

Some further ideas are to be found in the NSF for Long-Term Neurological Conditions.

4. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?

- a. From our experience of working with people with dementia we know that schemes such as direct payments are only appropriate if and when they are acceptable to the main informal carer. They must not be imposed in other circumstances.

- b. Policies must be developed to enable Continuing Health Care funding to be combined easily with direct payments or individual budgets. In appropriate circumstances, where this would make a package more workable, it should be possible for funding to be used for agency staff rather than being restricted to staff employed by the NHS or Social Services as regulations have required until recently.

5. What can you or your organisation do to help implement the recommendations?

- a. The BSRM will readily support the recommendations and ensuing strategy and will work to make links between the strategy and implementation of the National Service Framework for Long-Term Neurological Conditions.
- b. We will want to work to ensure that the provisions are applicable to people with cognitive impairment due to neurological conditions, and that they support rather than undermine existing patterns of care for that group of patients.

Chapter 4 – Delivering the National Dementia Strategy

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

Yes

2. Is there anything that has been missed?

No

3. Priorities for implementation?

The highest priority must be to improve community care as outlined in Chapter 3.

4. What should the timetable be?

5. What can you or your organisation do to help implement the recommendations?

The British Society of Rehabilitation Medicine would be keen to contribute to the implementation process, through Rehabilitation Medicine being represented both nationally and regionally.

6. Does this draft strategy fully address issues of equality and diversity, and the needs of particular groups??

No: as emphasised above, we do not think that the needs of people with dementia associated with neurological conditions have been adequately addressed in this draft

General comments

Do you have any other comments you would like to make in relation to this consultation?

BSRM welcomes a strategic approach to dementia, but we urge that the strategy should be fully integrated with related initiatives and strategies relating to long-term conditions, including the Stroke Strategy and the NSF for Long-Term Neurological Conditions.