Cheshire East
Advisory Panel – People
23 September, 2008

Transforming the quality of dementia care: Consultation on a national dementia strategy.

June2008

RESPONSE TEMPLATE

Closing date for responses: 11 September 2008

Please send to: ***dementia.strategy@dh.gsi.gov.uk***

Alternatively, they can be posted to:

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Before submitting your response to the Department, please make sure that it has been saved in a name that will make it easier for us to track. Many thanks.

Respondent Details (Please provide the details of a single point of co-ordination for your response)

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If you are replying on behalf of a group of respondents or a number of organisations, please complete the following information:

Organisations represented within this response	Cheshire County Council Central and Eastern Cheshire PCT, Western Cheshire PCT, in consultation with Cheshire and Wirral Partnership NHS Trust

Response details

Date of response: **10.09.08**	**Closing date:** **5pm on 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?

The document proposes a full and thorough approach to awareness raising, which is an important aspect of work and describes significant input from local resources as well as nationally, targeting local employers and organisations dealing directly with the public. It recognizes the need for a cultural shift in public and professional attitudes to and knowledge of dementia, including understanding the positive help possible.

The development of national standards and competencies for staff will be helpful. The requirement that all staff working with people with dementia should be trained in dementia is welcomed and needs to be an ongoing process over the long term.

It would be helpful if the strategy identified links with the relevant strategies and developments in the workforce, education and training sectors and built upon these links and developments.

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

We welcome the proposal for national initiatives and campaigning. All forms of the media should be fully used for this. The development of training is also important but full implementation may take longer than the 5 year timescale proposed and will need to be an ongoing process.

Recognition and estimation of the costs this will entail would be helpful and recommendations on how this can be financed. Also, the likely effect on pricing of independent sector services and the subsequent effects on the social care market are significant factors, which should be considered.

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

Work with health promotion services to develop information and publicity strategy jointly. Use broader local authority networks such as through economic development, and responsibility for schools. Develop training and learning opportunities for staff. Work through Community Strategies, the LAA and LSP mechanisms to influence the involvement of partners.

Chapter 2 – Early diagnosis and intervention

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

The proposals for new and effective services for early diagnosis and intervention through a single point of access and service provision address a significant gap in current services. Services should be multi-agency, offering a range of interventions and information, including legal, practical and financial issues as well as signposting. Staff will need to be aware of the provisions of the Mental Capacity Act.

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

The success of the proposals will be dependent on the effectiveness of awareness raising for the public and professionals. The issue of meeting criteria for services is significant, including FACS criteria and access to “dementia drugs”, which have received very high profile and are often considered the main form of intervention. Funding availability for non-critical services and charging for these will impact significantly on implementation of these measures e.g. will the dementia care advisor be a service subject to charging by the local authority?

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

The strategy could be clearer about what it means in terms of specialist assessment. Certainly it should be made by services with specialist knowledge, skills and access to appropriate diagnostic tests. Recent reports show that GPs are currently ill equipped to offer reliable identification or diagnosis. However, local access and the “softer” end of identification, advice and information on maintaining wellbeing and managing some of the challenges of living with dementia should be available.

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?

Memory services should have referral systems open to all for advice and information as well as diagnosis. It is important that family and carers should be able to seek information and advice independently. Also GPs should be expected to increase their knowledge and skills in the area of older people’s mental health and dementia as they are a key point of reference for the whole population.

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

The ability of this new role to achieve continuity of care will be dependent upon good links with services that are part of a clearly defined care pathway of interventions and support which people need.

It would be helpful to clarify the relationship of the dementia adviser to advocacy workers, support workers, community nurses, CPNs, social workers, brokers and care navigators. Indeed it may be more helpful to think of this as a role, which could be agreed to be taken on by a clearly identified person from this range of people rather than a specific post.

Separating the post from existing posts role will not in itself achieve the desired outcome if appropriate services are unavailable.

Providers of care will also need to consider how best they can ensure continuity of care within their services. This could be a significant challenge in the organisation, funding and provision of home care services.

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

Local Authorities are charged with significant responsibilities for commissioning services, jointly with PCTs.

There are substantial issues in terms of commissioning capacity and in the availability of an appropriately skilled workforce and financial resources.

If the services achieve the aim of offering early diagnosis, timely advice, and information to the 50%-70% of people with dementia who are currently not identified, it can be anticipated that there will be greatly increased demand for scarce resources, which have not been costed.

Chapter 3 – High-quality care and support

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

The outcomes and propositions are wide reaching and ambitious and will significantly improve the quality and scope of dementia services, if fully implemented. The recommendations for leadership, training and registration in dementia care for all care homes and related commissioning practice reflect logically the proportion of service users who have dementia. However the impact on the care market in terms of price and workforce may be significant.

The timescale of 5 years is also very ambitious, and will need the release and provision of significant resources to implement the 'spend to save' approach.

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?

The extra and improved services outlined would ensure significant improvements. However there could be more detail and emphasis on the need to promote wellbeing and quality of life for people with dementia and their carers, including non- pharmacological interventions. The strategy could also place more emphasis on the need for jointly commissioned care pathways to promote best practice, reduce health inequalities and facilitate evaluation, ensuring value for money.

The consultation document highlights important links to carers' strategies but it would be helpful to strengthen this aspect of the Dementia Strategy.

There could also be more detail on the expectations of the role universal services could play in ensuring full 'citizenship' for people with dementia and their carers. Local, accessible services can and should have a higher profile.

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

The measures proposed are far reaching and should prove effective if implemented. However, some of the recommendations and propositions may be unrealistic in the short and medium term, as sufficient staff and financial resources are unlikely to be available e.g. the proposals for mental health assessment and review for the majority of people being admitted to and living in residential care. The availability of suitable home care staff and funding to train them is also problematic. A career structure for staff with enhanced skills may provide an important impetus, but this would take considerable resources and timespan to implement.

Understanding, knowledge and skills in person-centred care and responding to challenging behaviour are important in providing good quality care. The potential contribution of Dementia Care Mapping to improving quality of care, particularly in care homes, could be described. There could be greater emphasis on the need for co-operation and liaison between the network of services providing support to individuals and their carers.

It is to be hoped that the final strategy and implementation plans contain realistic, and challenging, targets linked to the national performance indicator sets, and clearly identify ring fenced resources to enable their achievement.

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

There will be a need to ensure that these systems offer sufficient information, advice and support to people with dementia and their carers and avoid unrealistic assumptions about their capacity for self assessment and care management. Choices available should include directly provided services, whether health or social care, independently provided or public services, including care management, advocacy and brokerage, without people being disadvantaged by price differentials. This can be important in ensuring continuity of care.

There will also be a need for systems for personalisation and individual budgets to ensure that people with dementia are protected from abuse, particularly financial exploitation, which has been identified as a significant risk for those people.

The issue of CRB checks and appropriate training and regulation of personal assistants is also crucial to the success of the personalisation agenda.

Chapter 4 Delivering the National Strategy

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

The establishment of national baseline measurements of dementia services would be helpful. However, it will be difficult to capture data from existing generic services, particularly considering the low level of identification of dementia and other mental health problems within those services.

In Cheshire most services for older people are used by all older people, including those with dementia. There are relatively few specialist services provided exclusively for people with more substantial mental health needs, including dementia.

2. Is there anything that has been missed to help us deliver the national Dementia Strategy?

The strategy identifies the levers for change, which may apply. However, the document also suggests that the recommendations are merely a digest of possible priorities and actions and that commissioning decisions will depend on local prioritisation and use of existing resources. Without a strong lead from central government, supported by targets and standards, local health and social care commissioners are likely to find difficulty in identifying the necessary resources to improve the quality of life and care for people with dementia and their family carers.

The strategy should contain explicit links with the national performance indicator set, and the priorities within Community Strategies, LSPs and the LAA, and an expectation that the strategy will influence partnership decisions on the allocation of resources.

3. What are your priorities for implementation? What can and should be done first?

The County and its Health Partners have already started to put mechanisms in place to ensure that the strategy for dementia is a key part of partnership working for the future.

Some priorities have been identified and these include development of crisis and home treatment services and improved access to intermediate care services.

At present there is a lack of comprehensive data available for a complete local strategy and the completion of the local Joint Strategic Needs Assessment in the coming months will be key to this. The strategy should make formal reference to the Joint Strategic Needs Assessments.

Some of the workstreams identified, including national initiatives, can be developed in parallel for example, investment in research, setting national standards for training and local initiatives to improve the quality of services.

4. What should the timetable for implementation be?

Given the scale of demographic change in Cheshire, it is clearly urgent that services for people with dementia are improved as a priority. However, a 5 year timescale for the scale of improvements identified is very ambitious without significant extra resources, clearly identified and ring fenced.

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

The National Dementia Strategy needs to take into account the special needs of those adults, under the age of 65, with early on-set dementia. They are much more likely to suffer from other forms of dementia than Alzheimer's disease, more likely to be in employment, to have school age children and have heavier financial commitment, such as mortgages and support to children in higher education. Also, the strategy needs to make more explicit recognition of adults with learning disability who are now living to an older age, but are more at risk of developing dementia type diseases in their mid to late 40's. Services for these people are often very fragmented, with service users falling between older people and younger adult's mental health services.

It would also be helpful to include further support and guidance to ensure that when implementing the National Dementia Strategy the cultural needs of all black and minority ethnic groups are being taken into account.

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

Local Authorities and PCTs in their community leadership role have an important part to play in developing the awareness and understanding of local communities and universal services towards those with dementia and their carers.

Local Authorities in Cheshire are about to undergo a reorganisation away from the two tier model of one County council and six city and district council to two unitary authorities. The publication of the final version of the strategy and implementation plan in October this year will be an important contribution in guiding future work and recommendations for the consideration of the two new Authorities which will be established in Cheshire in April 2009.

General comments

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

Cheshire County Council, Central and Eastern Cheshire PCT, Western Cheshire PCT and Cheshire and Wirral Partnership NHS Trust welcome the consultation document Transforming the Quality of Dementia Care, which raises the profile and highlights the need to develop appropriate services for the growing number of people with dementia, their families and carers.

We welcome the approach taken by the consultation document in recommending changes and improvements throughout health and social care systems and the challenges to our organisations. We recognise the costs and risks of changing nothing and will make the best use of research, guidance and resources to improve services for people with dementia in Cheshire. We also welcome the proposals for national and local initiatives to develop awareness, information, research and training.

However, it should be recognised that implementation of the strategy poses significant resource challenges to health and social care organisations in terms of commissioning, service and workforce development, which will be difficult to meet in the current economic climate, without increased financial support from central government.

The strategy identifies the levers for change, which may apply. However, the document also suggests that the recommendations are merely a digest of possible priorities and actions and that commissioning decisions will depend on local prioritisation and use of existing resources. Without a strong lead from central government, supported by targets and standards, local health and social care commissioners are likely to find difficulty in identifying the necessary resources to improve the quality of life and care for people with dementia and their family carers.

The collation of evidence on cost effectiveness recommending investment strategies, which will produce longer term cost benefits to health and social care systems as well as improvements in service choice and quality for people with dementia and their carers, is very helpful. Also welcome will be the further economic analyses planned for the final report.

However, there appear to be no plans to provide estimates of costs related to extra investigations, medication, care packages in the community or other previously unidentified needs and these are important aspects of improving dementia care.

This opportunity to contribute to the formation of the final strategy is welcome. However current commissioning work, such as needs assessment, is under development so that it is not possible to offer definitive responses in terms of priorities for development.