

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

June 2008

RESPONSE TEMPLATE

Closing date for responses: 11 September 2008

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

Alternatively, they can be posted to:

David Corcoran
Dementia Team
Department of Health
8E13 Quarry House
Quarry Hill
Leeds LS2 7UE

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)

Title	Mr
Full Name	Charles Wookey
Organisation	Catholic Bishops' Conference of England and Wales
Your Role	Secretary, Department for Christian Responsibility and Citizenship
Address (including postcode)	39, Eccleston Square London SW1V 1BX
Email Address	Charles.Wookey@cbcew.org.uk
Phone Contact	0207 901 4812

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	The Mission and Public Affairs Council, Church of England (contact: Malcolm Brown, Director of Mission and Public Affairs, Church House, Great Smith St, London SW1P 3NZ; tel: Malcolm.brown@c-of-e.org.uk ; 0207 898 1468)
--	--

Response details

Date of response:	Closing date: 5pm on 11 September 2008
<p>Confidentiality: Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes (these are primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).</p> <p>If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information that you have provided to be confidential. If we receive a request for disclosure of the information we will take full account of your request, but we cannot give an assurance that confidentiality can be maintained. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.</p> <p>The Department will process your personal data in accordance with the DPA and, in the majority of circumstances, this will mean that your personal data will not be disclosed to third parties.</p>	

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?

We agree with the need to improve public awareness of dementia and the proposals that the narratives of people with dementia and their carers would help achieve this. We also agree on the need for an informed and effective workforce. We welcome the emphasis on working to tackle stigma and public misunderstanding about dementia.

Person-centred care for people with dementia requires a considerable depth of relationship with the carer. When personhood is understood as both biological and biographical, it becomes possible to understand the physical needs of a person with dementia in the context of their life story, and this is often crucial in interpreting their wishes and needs. It follows that the role of the carer should be conceived as being much more than an anonymous functionary. Person-centred care means that carers need to form a relationship with the person for whom they are caring which goes beyond the mere carrying out of contractual duties. Whilst proper safeguards must, of course, be in place to prevent inappropriate behaviour, there is a real danger that excessively bureaucratised structures of caring will prevent the development of the kind of relationships that would maximise the benefit to the person with dementia.

We are particularly interested in the recommendations on professional training and education and workforce development. We would like to see workforce development interpreted in as broad a way as possible to incorporate those from faith communities working with people with dementia and their carers. Churches have much to offer but those involved need training and development in order to develop their own awareness and skills base.

We would like to see training and development underpinned by a set of values focussing on a 'whole person' approach to the care and support of people with dementia. In our view, understanding of spiritual and religious needs form an essential part of a 'whole person' approach to the care and support of people with dementia and well as their carers. As memory and communication skills diminish with the advance of dementia it is particularly important to stress the importance of 'personhood' as a prerequisite to understanding and meeting spiritual and religious needs.

We welcome the statement on the need to treat people with dementia with dignity and respect. In our view it would be helpful to provide examples where these principles underpin everyday practice, not just in combating stigma but equally in caring for people with advanced dementia as well as in end of life care.

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

We welcome the recommendation to provide positive messages and to combat stigma and public misunderstanding. We believe that people with dementia should have the same opportunities for social inclusion as other service users – and parish communities are often well placed to achieve this.

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

Faith Communities have a significant role to play in the developing awareness of the needs of people with dementia as well as their families. In addition to the clergy, significant numbers of lay people are involved in pastoral as well as outreach work. There is further work to be done in ensuring that religious services social and cultural activities focus on the needs of people with dementia. Faith Communities can also provide much needed support for informal carers.

A number of recent policy initiatives, such as the NIMHE/CSIP Spirituality and Mental Health Project have provided a useful springboard to address these issues over recent years. In 2006 a parish resource booklet was produced by NIMHE, the Church of England and Mentality. The Catholic Church is currently developing the 'Everybody's Welcome' Initiative.

This interest has now been widened to cover dementia and had been taken forward by a number of specialist voluntary organisations. For example for example the Pastoral Care Project in Warwickshire (www.pastoralcareproject.org.uk). Organisations such as the Leveson Foundation (www.leveson.org.uk) and the Christian Council on Ageing (www.ccoa.org.uk) have developed awareness over these issues. Professional groups such as the Spirituality Special Interest Group of the Royal College of Psychiatrists (www.rcpsych.ac.uk/spirituality) have been particularly helpful in identifying the need to ensure links between dementia and spirituality.

The CSIP Dementia Collaboratives have in some cases developed special interest groups with a focus on spirituality – for example a conference on Dementia and Spirituality in Kent earlier this year was sponsored by the South East Collaborative.

Some examples of Church based activities are as follows:

The Church of England has developed a network of Diocesan Advisers with a particular focus on dementia to work with parishes on developing inclusive parish communities

Caritas Social Action Network, an agency of the Catholic Bishops Conference of England and Wales (CBCEW), is developing a dementia project to raise awareness and provide training within the Catholic Church on dementia related issues.

The recent 'Faith in Health' Conference organised by the CBCEW, focussed on how to take these issues forward.

Methodist Homes for the Aged have developed some useful training resources on dementia related issues.

'Candlelight' services, with a focus on meeting the religious needs of people with people with dementia in an accessible and appropriate way.

The 'Person Centred Churches' initiative has been promoted in East Kent as an example of good practice in the Church of England.

We recognise that there is much to be done and we would welcome further discussion on how additional resources for training made available through the strategy could assist awareness of dementia across the range of Faith Communities.

Chapter 2 – Early diagnosis and intervention

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

We welcome the emphasis on early diagnosis and intervention in dementia. This will enable those with dementia as well as their carers to lead as full a life as possible. We are concerned that the assessment process should be based on a 'whole person' approach and that those involved in assessment, both in primary care and in specialist memory services should be trained in exploring issues of spirituality and religious practice as part of the assessment.

We see this as part of a strength based approach to assessment – to explore 'the connection which brings faith, hope, peace and empowerment' (Tanyi). Early intervention may also be an opportunity for preparation for end of life - for example an opportunity to decide on funeral arrangements while the person still has capacity.

A whole person approach must take due account of the network of relationships within which the person with dementia lives. This has implications for questions of confidentiality which need to be addressed urgently. The assumption that every patient is an autonomous individual and the consequent assumption that conversations with the medical profession, diagnoses, etc. cannot be shared with close relatives, carers etc needs to be carefully and cautiously relaxed to enable the person with dementia to be held within a loving and well-informed network of friends and family wherever this is possible.

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

We would like to draw attention to the particular needs of carers. These needs are often articulated in parishes and it is important for those concerned to be able to support carers effectively through awareness of services such as memory services.

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

No comments on this section

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?

In our view access should be as open as possible consistent with resource constraints

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

We hope that Dementia Care Advisers will be sufficiently well informed to be able to signpost people with dementia and their carers to Churches and Faith Communities as appropriate.

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

Faith communities are well placed to signpost carers, families and sufferers from dementia to appropriate sources of help. For many in a position to offer help and advice, the concern is often 'we don't know where to go'. Good quality information about local services, for example memory services, would address these concerns.

Thank you

Chapter 3 – High-quality care and support

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

Overall, we believe that the outcomes, recommendations and suggested means of achieving them are appropriate.

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?

Role of Commissioners. Commissioners have a key role to ensure that services are person-centred; provide dignity and respect, as well as being clinically effective. We would like this approach incorporated in the service specification of services with a specific reference to meeting the spiritual and religious needs of people with dementia as well as their carers. We would also like to see more emphasis on the need for culturally competent care – this in turn will encourage a focus on meeting spiritual and religious needs.

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

Acute Care. We would like to see more emphasis on the importance of Chaplaincy services in addition to the range of other services described in the strategy. We would also like to see more emphasis on understanding and meeting spiritual needs in Acute settings, and in particular on acute assessment and treatment wards. In our experience good spiritual care, linked to the needs and choices of the individual, can bring comfort as well as reducing levels of disturbance. For example, for some people with dementia the provision of a Rosary, or the encouragement of other forms of habitual and structured prayer, can be particularly helpful. Familiar prayers and hymns and 'Candlelight' services can provide a link with reality and reduce disorientation.

Continuing Care and End of Life Care. We are concerned that there is little mention in the Consultation about the need to promote good practice in Continuing Care provision for those with advanced dementia. In our view this is an area which needs to be addressed – both in terms of the spiritual and religious care needs and in promoting dignity and respect. We would also like to see end of life care issues considered – for example how those meeting the spiritual needs of people with dementia at the end of life can learn from best practice in hospices in providing spiritual and religious care. See above for some examples

Home Care. We agree on the need for a personalised and flexible approach to home care services and that rigid, time based services do not promote a person-centred approach which in turn underpins a positive approach to understanding and meeting the spiritual needs of people with dementia. We suggest that home care workers should have training in this area so that they in turn can assist and sustain people with dementia in meeting their inner needs as well as their physical needs. For example a carer could support someone with dementia to say familiar prayers at the start and end of each day. Carers and support workers should be aware of opportunities to attend local Churches in order to preserve and nurture well established religious practice as a source of comfort and hope.

Care Homes. A number of providers, for example Religious Congregations as well as organisations such as Methodist Homes for the Aged have developed a specific ethos with a focus on meeting the needs of the 'whole person'. This is done through embedding this approach into daily care routines such as morning and evening prayer where the person so wishes. Other more common examples are the provision of specific religious services and individual ministry such as providing Communion. Activities such as reminiscence therapy can and should focus where appropriate on addressing spiritual and religious needs.

We need to beware of the potential for excessive 'bureaucratisation' of care, for example through an over-emphasis on risk management. (For example we note the disappearance of candles - which are important symbols for people with dementia - in many residential homes and care settings to comply with health and safety risk assessments). The disabling effect of excessively bureaucratic approaches – not least, in inculcating a deep reluctance among carers and other service providers to take initiatives or to do anything that is not explicitly prescribed – should not be overestimated. Satisfactory care of people with dementia requires that carers are able to respond with common sense at a human level to the needs of the whole person.

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

We see the process of personalisation and the agenda set out in 'Transforming Social Care' as an opportunity to enhance the way in which the spiritual and religious needs of people with dementia and their carers might be met. For example, within an individual budget, provision could be made for transport to a Church based social activity which might otherwise not have been possible. Personal Assistants, employed through an Individual Budget, could assist people in meeting their 'inner' needs in a more flexible and person-centred way than someone employed through a care agency. Carers might benefit from a retreat and an opportunity to meet their own needs – there are a number of examples of good practice in this area.

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

Chaplains, priests, lay workers and parish communities are well placed to support practice which is based on meeting the needs of the 'whole person' in many ways. We note that older people are a highly spiritual and religious group (Higgins, 2003) and that for people with dementia it is difficult and distressing to hold on to their sense of identity as they struggle with memory and communication. While recognising that in a multi-cultural context we must not be prescriptive, we believe that there are times when spiritual and religious care is key to the overall provision of care for a particular individual.

There are many examples of good practice – some of these are listed above. We acknowledge the need for further training and support in this area for those involved in providing spiritual and religious care and look forward to working in partnership with key stakeholders to achieve this.

Thank you

Chapter 4 – Delivering the National Dementia Strategy

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

See below

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

Please see our comments in other sections of this response. Overall we believe that the spiritual and religious care needs of people with dementia should be given greater prominence in the strategy.

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

Whilst we recognise the focus on developing assistive technology to enable people to stay in their own homes, we would also point out that in spite of these helpful initiatives the proportion of those with dementia entering long term care is still set to rise over the next ten years. We need to ensure that the care and support needs (including spiritual and religious care) of an increasingly dependent group of people are addressed notwithstanding the need for early intervention. We hope that the implementation plan for the strategy will recognise this.

4. What should the timetable for implementation be?

No comments on this section

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

See above.

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

While our response is primarily Church based, we believe that the strategy should address more fully the issues in providing genuine culturally competent care. Staff in home care, acute settings as well as in home care need to be fully aware of the cultural aspects of a wide range of religious traditions, including dietary and religious practice requirements. People with advanced dementia may be unable to express themselves, but liaison with families and understanding of specific requirements, for example over end of life care, is essential to good spiritual and religious care for people with advanced dementia.

Thank you

General comments

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

Overall we would like to emphasise the importance of a 'whole person' approach in the care and support of people with dementia. This must include a focus on understanding and meeting the spiritual and religious practice needs of people with dementia and their carers. We would be interested in exploring with the implementation group the ways in which our Churches and other Faith Communities can be seen as partners in developing effective and inclusive resources for people with dementia as well as their carers.

Thank you