

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:

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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	
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Response details

Date of response:	
Closing date: 5pm on 11 September 2008	
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Views are sought on the following:

Chapter 1 – Improved Awareness

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

- a. There needs to be a stronger emphasis on prevention. It is at the bottom of the list of the information campaign. It mentions cerebrovascular health for which we have some evidence. But it is crucial to raise awareness about what people can do to lower their risk, including habitual aerobic exercise, mental stimulation and social interaction. Don't wait for evidence before advising people to live a healthy active lifestyle. Even if it doesn't prevent dementia in them, they will be healthier while living with it.
- b. The strategy predetermines the perimeter within which dementia care sits. This is a major flaw as it keeps people with dementia within a medicalised model of care, which from my research and practice I know to be detrimental to emotional, physical, psychological and spiritual well-being. The awareness we desperately need is at the decision-making level. Carers, care practitioners and people with dementia themselves are already aware that normalised, enabling treatment is helpful and necessary, but the trickling up to policy makers is not happening fast enough, it at all. The mental health services approach is damaging to the mental health of people with dementia who rarely identify as ill in any way. The longer a person has dementia the less aware they are of any of the problems WE say they have. Going along with their self-perception is required if we are to contribute to their mental health rather than undermine it. To contradict a person's sense of self, to control, manipulate or manage them to satisfy our own needs, is to contribute to the decline of their mental health.
- c. The emphasis on training is not helpful if it narrowly defines knowledge, disregarding practical knowledge, learning on the job, life experience, intuition and common sense. Statutory and formal training should not dis-empower caring individuals by valuing credentials over compassionate and good-hearted experts in human relationship. What is needed most is the good old-fashioned, person-centred techniques and methods - the only sure way of breaking through the 'us' and 'them' which is so prevalent nowadays.

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

a. In terms of awareness it is important to get the message out that dementia is strongly affected by the person's environment. The strategy largely ignores housing and the physical environment when in fact the environment plays a role on par with care provision. These are equally weighted in terms of the positive or negative effect they can have on a person with dementia. A exclusively care service-centered approach is only half the story as it leaves out care environment. As a disability, which dementia is, the role of the physical environment supports and promotes well-being by enabling a person to remain as independent as possible and to retain life-long skills. But poor quality care practice or physical environment / housing will de-skill a person, contributing to an increased need for care services. Furthermore, de-skilling and a disabling environment increase so called 'challenging behaviour' which adds to the stress of an over-burdened and underpaid workforce, as well as the emotionally stretched, physically stressed and under-resourced army of family carers.

b. It is unethical to simply raise awareness of dementia if you are not also helping people understand what can be done, what works, what people with dementia enjoy, where the hope is and so on. By this I do not mean drugs or cures, but things that increase quality of life for people with dementia right now. Most importantly, what can other people do to increase quality of life for a person with dementia? So you are not just giving bad news and terrifying people. No wonder people avoid assessment and delay diagnosis if they fear there is no hope of any sort of a decent life. Examples of good life quality must be made known. Much enjoyment comes from a connection to other people and to nature. If carers and people with dementia are aware of such things they will be able to expect and demand appropriate living environments that are fit for purpose. Many carers have low expectations about care environments, and therefore will settle for an institutional regime. This then becomes a self-fulfilling prophecy as their loved one declines rapidly in such a place with little or no communication, activity or social interaction.

c. In terms of awareness more needs to be done to both inform young people about dementia at the same time providing opportunities for them to become involved in supporting and caring for people with dementia. Intergenerational programmes are a benefit to isolated and disenfranchised groups – young people and older people can both fall into this category. Open up channels of communication between the young and the old. There are two groups of young people whose awareness can be raised. School aged children are a real pleasure for older people to talk to and watch as they play. Teenagers also can benefit from being around older people, especially if they have no grandparents themselves. Awareness is best achieved through personal relationships. Knowing someone with dementia personally raises awareness most effectively, because it puts a human face on the disability.

d. Awareness raising - about dementia should not consist of fear mongering about how horrible and devastating the disease is. This only serves to reinforce stigma and to distance people without dementia from those with it, out of fear and revulsion. This is not helpful, nor is it where we need to be heading. It reinforces a person's condition when they are being poorly cared for. But there is a great deal of well-being that is possible for a person with dementia, given enlightened care practice and an enhanced and enabling environment. This is the story of dementia that must be told, rather than reinforcing and perpetuating poor practice by spreading this scenario, as if it is the dementia that causes this. In fact, dementia can be a positive experience for many people. Dementia per se does not create a horrible experience for people (once they have accepted what is happening to them). It is the poor care environment and negative interactions with others that create ill-being, during which behaviour deteriorates.

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

I regularly give public presentations, lectures and training sessions to staff and carers, academics and practitioners. I also design environments to improve quality of care as well as consult on the building and landscape design of new and existing facilities.

Chapter 2 – Early diagnosis and intervention

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

- a. Early and accurate diagnosis is important if the carers need it. And also if having a diagnosis does in no way negatively affect a person's opportunities, rights or life style possibilities. I don't believe a diagnosis should be a gatekeeper for funding of any kind. If a person is concerned about their memory or their ability to function properly, support should be available. A diagnosis is seen as the silver bullet. Once it has been given, problems will somehow get sorted. If an assessment is required for funding for placement in care or for access to services then it should be available to anyone who asks for it.
- b. Having a diagnosis should not be a requirement for services and transport. It should be made clear what the implications are for a person if they are given a diagnosis so they can choose whether or not to have an assessment.
- c. Early diagnosis can be positive in terms of long range planning, living wills, etc. More people live at home with dementia than live in care. Their ability to continue to live at home with support should not be infringed by a diagnosis.
- d. Memory assessment should not be tied to a mental health service but should be a separate specialist service. For one reason, this is because memory is an activity involving more than just the mind. The person remembers in their heart and body as well. Cognition tests are largely irrelevant when it comes to assessing a person's ability to be happy, which in turn affects their ability to carry out tasks. A person with dementia can respond to rehabilitation. Some amount of re-skilling is possible as well as training to enable a person to stay well for longer.
- e. Intervention should be available to combat loneliness and depression, as a preventative to dementia. Save time and money in the long run by catching people before they develop dementia. Reach people who are at risk and offer them support and resources to prevent an eventual decline into dementia.
- f. Recognise the connection between traumatic life events and the decline into dementia. This happens in the majority of cases I have witnessed over the last decade. Should we not be providing community, support and friendship to widows, widowers and people who have suffered the death of a child, as a matter of course? I believe this could postpone if not prevent many cases of dementia.
- g. If a diagnosis is required for access to services then they need to be worth accessing. They need to provide physical settings where people can be happy, comfortable and enabled.
- h. Recommendation 4: "developing a comprehensive package of high quality information to be given out...." is not useful. During a stressful time it can be overwhelming. It also makes it the carer's responsibility to read through and digest all this, decide what is relevant to their situation and then act on it. They are at wit's end or they wouldn't be coming in so don't overburden and confuse them even more. This sounds like a way to relinquish responsibility for a person-centred approach, where practitioners or whoever the point of contact is, can get to know the individual's situation and life history and help the person to make the right choices for themselves. This is a quality service, whereas a stack of paper is not. And don't think about (only) putting it on the web. If people want to learn computers they will on their own, but should not be required to learn under the pressure of an already stressful situation. Handing out information sounds akin to personal budgets. All this information should be available for people if they choose to access it. Again, sounds like the resource centre role is more useful.

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

- a. Make sure practitioners are aware of the early symptoms and refer people to get an assessment. Make sure the person with dementia will be supported with whatever services and advice they will need, or else they will not follow up the referral. Services and physical environments must be top rate so people are relieved if they go ahead and get a diagnosis, not sorry they did.
- b. I don't believe a diagnosis can be both quick and high quality. People with dementia have good and bad days, so one day is not a complete picture. It is also unfair and misleading to assess a person away from their own familiar environment. The added stress of being in a medicalised place that looks and feels like a doctor's office, when the person may be asked to make a cup of tea, for example, does much to unravel confidence and increase the possibility of failure. Assessment measures a person's level of failure, which can only lead to more. We need better tools that give a more accurate measure of ability and need, so these can be supported and met, rather than measuring deficits and labelling a person accordingly.

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

Why can't it be a team who have a range of different types of knowledge, instead of just a medical practitioner/ doctor/specialist?

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?

Totally open to anyone who is concerned about themselves or a loved one.

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

Not sure this will help – one more thing to go wrong, break down or go missing. Shouldn't the system as it is configured 'enable people with dementia and their carers to obtain the help, care and support needed quickly and easily' (p38) without guaranteeing or attempting to guarantee it with one person? If such a person is needed then the system is not user-friendly and not fit for purpose. The resource centre model is a more robust approach and provides not just a person with information but a community with support – worth their weight in gold to families and people with dementia – and available when people need it.

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

I am not involved in diagnosis and intervention directly but do advocate for a humane approach in normal domestic environments through my teaching and training activities.

Chapter 3 – High-quality care and support

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

a. The recommendations seem reasonable but the underlying premise is flawed. Dementia is being treated as something out of the norm. Do we need a specialist liaison team when a person comes through the door in a wheelchair? Dementia is a disability that affects the way that person interacts with their environment. A high degree of well-being is possible until their final day, given appropriate support. Stop forcing people with dementia into the mental health straight jacket and then configuring services accordingly. A person with dementia has 'living difficulties' (sound familiar?). They are not mentally ill and certainly not 'mentally infirm'. Their quality of life is compromised by inadequate support, care and environment, which leads to behaviour appropriate to the situation. The behaviour is not the dementia, it is a response to lack of proper support in a normal familiar environment. There are more people out here with dementia than with a diagnosis. So when will the hospital know when to use the pathway and the team? It's going about things backwards. If "70% of acute hospital beds are currently occupied by older people and up to a half of them may be people with cognitive impairment, including those with dementia and a delirium" (p41) then up to 35% of hospital beds are occupied by a person with dementia. One in three? The hospital system must upgrade their approach to accommodate their client base.

b. A joint commissioning strategy is definitely necessary. But the issue of funding of social care is not addressed. Care home, home care and short break services are underfunded when you consider that as much as 60% of people in these services have some level of dementia. We know the problems (transitory workforce, minimum wage/commitment, language skills, low work satisfaction, career path...etc.) and yet the funding is not there to solve them. The NHS continues to wash their hands of funding responsibilities because of false divisions (between health and social care primarily but also between adult services and older people's services). When a person turns 65 they are dumped onto the compost heap of old age. The person and their needs have not changed. This is blatant institutionalized ageism. But back to the health and social care divide. Building a high quality well-funded social care system must be cheaper in the long run than paying for expensive crisis intervention, hospital stays (for preventable problems like infections, dehydration and malnutrition), hip-replacements (instead of falls clinics, exercises and walkable communities) and long-stay inpatient facilities...all for people with dementia because their conditions decline as a result of poor quality care. They need personal care and attention, social life, activities, day trips, support for family carers and so on in order to stay well and avoid high cost medical interventions. Surely a home visit of one hour is still cheaper as a preventative, than that person ending up on a long-stay psychiatric ward, doped up, slumped over and incontinent to live out their life in captivity?

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?

- a. Can we realize that the behaviour of a person with dementia is a logical result of their sensation and perception of their environment (people, physical and natural world), and is therefore derived logically, just like anyone without dementia. Behaviour is not dementia, it is a response to changing perceptions which in turn are not supported environmentally. Create the supportive environments (people, physical, natural) to enable life and behavioural problems are solved – without depersonalized medical-style (i.e. costly) interventions.
- b. Environment, Environment, Environment!...housing, extra-care, day care, telecare must be integrated into a comprehensive systems approach. But even these need to be based on progressive enlightened models. Day care is not just sitting around a room in chairs. Need to integrate rehabilitation and re-skilling into care services and this requires properly equipped, furnished and laid out places.
- c. Need more involvement by occupational and horticultural therapists with people with dementia.
- d. Nature, outdoor areas, parks, green space, patios, porches, arias, water features, seating, wildlife habitat, walkways, allotments, animals, pets....the list is endless of ways that nature can and must be incorporated into care practice. The indoor and outdoor environment must be fully integrated, as must care practice to include normal, daily, meaningful outdoor activities into day to day life. www.chalfontdesign.com
- e. Under Recommendation 12: improved registration and inspection of care homes, when determining whether or not it is a good environment for daily life for a person with dementia, the environment must show evidence of being designed and used for familiar meaningful activities. There must be tables and chairs, shelves, fixtures and fittings, items for people to pick up and use and much more. A home must look, act and feel like a home or it continues the sham of an institution with curtains. Not just ornaments but practical devices and equipment are required to involve people in daily tasks. Residents need sinks and sheds, radios and clothes lines, kitchens they are assisted to use, meals they contribute towards, private cosy spaces to share time with family members, gardens where they can grow and eat food, play areas for children both indoors and outdoors...the list is endless but the reality is practically non-existent. **A strategy that does not enable environments for proper living will not address the core issue for a person with dementia – the regulated, institutional, systematic removal of a disabled person from normal life, from citizenship and from mainstream culture.**

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

- a. It is not just people with dementia who would benefit from improving home care services. The short, fast, task-oriented approach does nothing to support the person emotionally or socially. My feeling is that if the person is at risk for dementia, when areas of personal / emotional support break down, his or her dementia is likely to develop sooner than if they were feeling connected to a community of caring people through physical activities and social interaction. It is no wonder why the delivery of tasks devoid of human contact and meaningful conversation is so prevalent in care homes, when people living at home are being groomed for it. Why does the strategy attempt to solve core problems by applying some 'specialist' model? Improve the basic approach and ensure the quality is high there. By adding some gourmet version you only reduce the acceptable quality of the standard fare. Surely we need to invest in improving what will then be acceptable levels of care for everyone? People develop dementia over a period of years. By focusing on people identified with it we are probably increasing future incidence rates by allowing a lowered standard of care for everyone else, including all those people developing early signs of dementia as we speak.
- b. Hospitals are challenging environments for people with dementia in part because they are places where the medical model rules, and a lower value is placed on human contact, emotional support and spiritual well-being – essential factors in the healthcare of a person with dementia. Even social care environments at their worst afford some recognition of the person, whereas the medical model is based on a treatment approach which sees a body and mind that is sick and needy, not an individual participating in their environment. Recommendations for improvement, management, care pathways, training and so on must be developed outside of the medical model (the treatment and recovery model) and in line with an ongoing care and support philosophy.
- c. Can we move on from the draconian health and safety approach to environments where all risk is farcically removed? Normal life is against the law because human rights to fresh air and movement are denied, self-identity through meaningful occupation is diminished, relationships to people and nature are severely compromised and poor care practice is enabled if not encouraged. Instead of care enabling life it simply provides service, but it does so at a cost to the normal, familiar, domestic and small-scale – all qualities of spaces and design criteria the experts tell us we need to be promoting. Warehousing of older people is the result where quantity of life is prioritized over quality.
- d. There is a limit to what care homes can provide. They are already overburdened with regulation, paperwork, staffing problems, lack of funding, expectations from everyone (family carers, residents, regulators, health and safety, councils, etc.) and their burden grows. All the negatives are increasing (elder abuse, infections, hospital visits, complaints, empty beds, running costs, burn-out, vandalism, competition, regulatory changes and demands as well as abuse by staff of liberal sick-leave and benefits policies, encouraged by GPs handing out sick notes). The list is endless. They are expected to explicitly own dementia as well (p46)...but they will not be funded to do this!

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. I suggest the resource centre model be taken up and promoted. See a working model in Charnley Fold, South Ribble, Lancashire. It involves the voluntary sector as well as carer and patient services. It has a fantastic outdoor garden environment and great integration of indoors and outdoors. (Ivan Lewis visited in June 2008)
- b. Can people not give their personal budget to a centre and then better allow them to provide a full range of services customised to individuals? This makes more sense than expecting individuals to all become experts in what is available, how the person with dementia might benefit, how to go about accessing it and so on.

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

I am applying my efforts towards increasing the well-being of people with dementia and their carers through design of environments and care practice. Settings including day care, care homes, nursing homes and neighbourhoods in the UK and abroad. Methods include training, teaching, research, landscape architecture, environmental assessment and architectural design and consultation. As an employer I also work to improve the skills and understanding of design professionals who work with me.

Chapter 4 – Delivering the National Dementia Strategy

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

- a. Recommendation 14: A clear picture of research evidence and needs. It is not enough to identify the existing research base and the gaps in it. We need to see what is actually done with the results and findings to actually improve lives for people with dementia. Based on that information the general public should play a role in deciding how their taxes are best spent on dementia research in the future. Ensure findings that people can benefit from actually reach them. Does the person on the street who is paying for it actually know where we stand in terms of prevention, cause, cure and care?
- b. While there is discussion in the strategy about “a range of supported housing options” and ‘new care models’ (p53) it also says, “In the coming years, consideration will need to be given to the role that both traditional and emerging models of long-term care provision (either at home or in care homes) should play in supporting the projected increasing numbers of people with dementia.” (ibid) My point is that on the one hand it sounds progressive but on the other we are still settling for either being at home or in a care home. This is an unacceptable plan for people who are living a hundred years - that a person with dementia may face decades of life incarcerated in the *faux* institutions that care environments are steadily becoming (larger, under-resourced, more restrictive). In communal areas of the newer care homes we are back to Bentham and the panoptical space! (Dementia shortens life but with newer drugs I can envision longer survival.)
- c. If the strategy takes on board the need for a re-alignment of dementia away from mental health services, then the delivery strategy will have to radically change. But if not and the recommendations included in the strategy as it stands go forward, then I am not confident that much of it will happen. Recommendations for quality of care for older people generally have been written up in earlier government manifestos (for instance the NSF) but the reality wasn't met. The reasons why the will or the mechanisms were lacking must be addressed or the same thing will happen with this.

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

Political will power and an appropriate level of funding.

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

Strategy overall

- Separate out dementia from mental health services
- Link physical health care services into dementia teams
- Take environmental issues on board

Projects

- Home care and neighbourhood support services such as day care - to help slow the pace at which people are developing dementia in the first place
- Resource centres (see Charnley Fold, South Ribble, Lancashire)
- Supportive housing and neighbourhood options - so there is something other than living at home or living in a care home

Funding

- Look at the whole picture in terms of funding and more realistically invest proportionate to where people with dementia are already being cared for. In care homes for instance provide more reasonable levels of support (not just from the NHS but from housing) to match the level of the population of people with dementia who are living there.
- Have PCTs reappraise their need to fund different supports - move support across the system from acute services to social care and care in the community

4. What should the timetable for implementation be?

Address everything at once but with individual time frames as some things will take longer than others. All change please, all change.

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

I am working at the forefront of innovation in design for dementia care environments

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

Cultural needs are firmly rooted in space, place, and social interaction. So to ignore the spatial imperatives of care generally, which the strategy does, is to particularly ignore the needs of various ethnicities.

General comments

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

Nobody related in any way to the built environment was involved in the groundwork for the strategy, with one small exception - Housing 21 was listed under 'contributions also received'. The strategy was written in a vacuum, with the perception that care somehow magically occurs floating in thin air. The recommendations likewise pay lip service to environment but show no commitment to the reality that physical space has any meaningful effect on a person with dementia, let alone their well-being.