counsel + care

for older people, their families and carers

Counsel and Care consultation response

Department of Health

‘Transforming the quality of dementia care’: consultation on a national dementia strategy

September 2008

About Counsel and Care

Counsel and Care is a national charity getting the best care and support for older people, their families and carers. We work with older people and their carers to ensure they are aware of and receive their rights and entitlements, and promote choice and control in later life. We operate an advice service, which deals with around 250,000 enquiries per year, through telephone calls, emails, letters and our website. The frequency of contact we have with older people and the issues raised through this service are used to inform our campaigning and lobbying work.

The advice service is an expanding part of the organisation as ever-increasing numbers of people are in need of advice and guidance about issues affecting older people, particularly on care and support. Enquiries are answered in detail and are followed up with a tailored letter which emphasises the options available in each case, and which provides a resource, which people can revisit for guidance.

Counsel and Care receives a large number of calls each year from families and carers who are concerned about whether their older relatives with dementia are receiving the most appropriate and high quality care that meets their needs in the setting of their choice. Enquirers are also concerned about situations where the wishes and

wants of the older person with dementia seem to be disregarded in favour of the opinions of professionals under an assumption that the older person has lost mental capacity for all decision making.

Counsel and Care's response

Counsel and Care has considered the consultation document released by the Department of Health on 19 June 2008 and has a number of comments to make on its proposals.

Overview

Counsel and Care welcomes the publication of the first National Dementia Strategy. We agree with the care minister, Ivan Lewis, about the urgency for dementia to be brought 'out of the shadows', as a result of this strategy. This is especially important if the demographic reality of the future is considered: the number of people living with dementia in the UK is predicted to rise to nearly one million by 2025 (Dementia UK, Alzheimer's Society, 2007).

The proposed strategy contains a five-year plan, which if fully implemented, with the appropriate resources it deserves, could indeed 'transform' dementia care and with it, the lived experiences of older people with dementia, their families and carers.

However, this statement does contain a big 'if'. Such an ambitious vision for high quality care must be backed with a fitting amount of funding if it is to encourage meaningful change on the ground in the long-term for older people with dementia receiving care and support. It should also work to make a cultural shift in understanding both in the social care workforce's level of expertise and in public awareness.

In addition to money, this strategic vision for the future is also restricted by huge current problems within the care and support system: councils increasingly restricting

their eligibility criteria (subject to review), high numbers of self-funders becoming 'lost' to the system and long waiting lists for assessments, care and equipment.

Early intervention is vital for timely treatment of people with dementia, but seemingly very difficult to achieve in the current climate. Council provision for lower level care services vital to maintaining an older person's independence and dignity, and ensuring they remain an integral part of their local community, have all but disappeared across England. Instead, exhausted families and carers or over-subscribed voluntary services are bearing the brunt of this 'care crunch'.

The current system is also undermined by its propensity to hit the vulnerable hardest so they struggle with complex needs while having to pay expensive care bills. As was highlighted in the results of Counsel and Care's annual care charging survey: *Care Contradictions 2008: putting people first?,* charging for care is ever-increasing, hitting £18 an hour in one council surveyed, at a time when the quality of care often doesn't mirror this increase in expenditure. CSCI has found that the rate of improvement in care services is slowing down 'for the second year running' and 'not all services are meeting all of the national minimum standards', five years after implementation (The state of social care in England 2006-7, CSCI).

Finally, Counsel and Care considers that this national dementia strategy cannot stand apart from the other strategies that have been published recently. It needs to interlink with the End of Life Care Strategy, the Carers Strategy and strategies on lifetime neighbourhoods and independent living to ensure that it makes the maximum impact on the quality of care and the lives of older people with dementia, their families and carers. In particular, creating homes and neighbourhoods that are good places to age within is part of Counsel and Care's wider vision of care and support for older people, their families and carers, and good housing must be developed to support people with dementia to remain socially included within their local communities.

Improved awareness

- *Recommendation 1: Increased public and professional awareness of dementia*
- *Recommendation 2: An informed and effective workforce for people with dementia*

Question 1: Are these outcomes and recommendations the right ones?
Counsel and Care agrees with recommendations 1 and 2. We consider it vital to raise awareness of dementia and its affects at public level. We acknowledge that this will not happen overnight: a sustained campaign is required to promote knowledge without sensationalising and stigmatising the issue. Such a prolonged public relations exercise must be approached with sensitivity, and must refer to the real lives of people with dementia of all ages, their families and carers.

Increased awareness is important for swift recognition of symptoms and timely diagnosis. It is also central to better understanding of the differences between dementias, stamping out discrimination after diagnosis in terms of continuing to work, access to services including rehabilitation and palliative care, mental capacity and decision-making, and also understanding of behaviours, such as wandering, sun-downing and possible aggression, and how to manage them appropriately.

Realising the implications of recommendation 2 is key to the success of the strategy. A powerful top-down approach is required to drive this forward, which ensures that dementia training is a core part of any care or health education programme, and commissioners recognise the importance of this when commissioning new services.

Question 2: Is there anything that has been missed to help us improve public and professional awareness of dementia?
It is also important to acknowledge that different levels of understanding are needed, according to the person's particular relationship to the older person with dementia. Clearly, the general public would need a lower level of knowledge and understanding to the person diagnosed with dementia and those interacting directly with them: the

relatives of people with dementia and their carers, and those working directly with them, such as care and health professionals.

Question 3: What can you or your organisation do to help implement these recommendations?

Counsel and Care has direct contact with older people, their families and carers throughout the UK through our Advice Service, our website, our networks and membership. We can actively support and promote a dementia awareness campaign both at local and national level.

Early diagnosis and intervention

- *Recommendation 3: Good quality early diagnosis and intervention for all*
- *Recommendation 4: Good quality information for those with dementia and their carers*
- *Recommendation 5: Enabling continuity of support and advice*

Question 4: Are these outcomes, recommendations and the suggested means of achieving them the right ones?

Counsel and Care considers recommendation 4 in particular to be central to the strategy, but must be extended: access to good quality and *independent* advice, support and advocacy must form part of this comprehensive package as well as 'information'.

Due to the complexity of the care system as it stands, older people with dementia, their families and carers require support simply to navigate their way through it successfully, and advice to be able to access the most suitable care to suit their needs and recognise and challenge the authorities if their rights and entitlements are not being met. Funding is needed to support this comprehensive package of high quality information and advice so it is a constant base for people with dementia to refer to that is linked to universal support for carers, and provides support along the whole journey, both pre and post diagnosis and the early and later stages of the disease.

The development of a ‘dementia care’ advisor role (suggested in recommendation 5) would be beneficial to the older person with dementia, and their families and carers. Such a role will be particularly helpful to older people during ‘transition’ stages, such as before and after diagnosis or when first requiring care and support to navigate the gaps and barriers that currently exist between care and health services. It is to be hoped that this role will serve as a preventative measure to empower individuals to access the right care and support before crisis point is reached and to support older people with dementia, their families and carers to challenge the system if they do not receive high quality care.

The development of the role may well be dependent on local determination of need in the area, for example, it might be attached to health or social care professionals or a voluntary organisation. However, we consider it important that the dementia care adviser is independent and not in any way responsible for direct provision of services. The dementia care advisor must be able to act as an impartial and unbiased source of information, advice and support, without any conflict of interest. Otherwise, there might be potential tensions in the role with other professionals in terms of recognition of the role (echoing the current problems independent advocacy faces), but also blurring the lines of responsibility, which still ultimately rest with the social care and health professionals.

Question 5: Is there anything that has been missed to help enable early diagnosis and treatment?

It is of concern that the UK inquiry into mental health and well-being in later life has found that less than half of older people with dementia get a formal diagnosis. With the emphasis on early diagnosis in the strategy, there is a likelihood that more older people will be diagnosed and get access to treatment. Key to improving the rate of diagnosis is to improve the skills of GPs and health professionals and to revolutionise the current culture which considers dementia ‘untreatable’ and confusion and memory loss an inevitable part of ageing.

Question 6: Do you agree that the diagnosis of dementia should be made by a specialist?

Yes, we agree that a specialist must make a formal diagnosis of dementia, but that GPs, health and care professionals, such as social workers or occupational therapists should be aware of the various potential symptoms and able to alert the relevant specialists to this.

Question 7: How open should referral systems be to a memory service? Should people be able to refer themselves, or should they go to a GP first?

With better public awareness and understanding brought about by the implementation of the national strategy, older people should have more personal control to self-refer to a memory clinic while also still retaining the option of going through a GP to a memory clinic, depending on their preference. It is important to have an open system and offer alternatives to encourage early presentation of symptoms, and therefore, more likelihood of early diagnosis and treatment.

Question 8: How would the dementia care adviser be able to ensure continuity of care?

The ideal interpretation of the role of dementia care advisor would be that the older person, their families and carers would have access to the advice and support of one constant person over a considerable timescale. However, this brings problems in terms of continuity. While it is unlikely that 'one' person will be able to provide support over the older person's whole life journey through the care and support system, it is important that their case is not 'closed'. Instead, there must be a seamless change over, where the baton of support must be passed on to another dementia care advisor from the same local 'team' to ensure continuity of support and advice. The older person or their family representative or carer must be able to present themselves to new advisor without having to explain their situation again from scratch. Counsel and Care's unique Advice Service is a good model to work from in terms of the detailed, confidential case notes that each advisor records after each contact to ensure continuity of advice and information.

Question 9: What can you or your organisation do to help implement these recommendations?

Counsel and Care works to promote understanding and provide in-depth, independent information and advice about care and support to older people with dementia, their families and carers over the telephone and through our website. Our Advice Service could actively refer our enquirers to local dementia care advisors while supporting their role by providing older people, their families and carers with high quality and in-depth information and advice via telephone and website.

Also, Counsel and Care, together with the Elderly Accommodation Counsel and Help the Aged, has formed the FirstStop Care Advice service. FirstStop is a new service for older people, their families and carers seeking advice on care, housing and finance. It aims to become the UK's leading source of independent, clear and direct information and advice on any kind of care and support for older people, their families and carers.

High-quality care and support

- **Recommendation 6: Improved quality of care in general hospitals**
- **Recommendation 7: Improve home care for people with dementia**
- **Recommendation 8: Improve short breaks for people with dementia**
- **Recommendation 9: A joint commissioning strategy for dementia**
- **Recommendation 10: Intermediate care for people with dementia**
- **Recommendation 11: Improved dementia care in care homes**
- **Recommendation 12: Improved registration and inspection of care homes**

Question 10: Are these recommendations and the suggested means of achieving them the right ones?

Formal recognition of the specific needs of people with dementia in hospital is vital in terms of the treatment they receive within the hospital and the discharge planning (recommendation 6). In particular, in terms of orientation within the hospital, it must be confirmed in hospital policy that older people with dementia must not be frequently moved from ward to ward during their hospital stay. This is especially significant for the care of older people with a complex combination of needs, such as

mobility problems, sensory impairment or a chronic medical condition in addition to dementia.

Currently, older people with dementia suffer the most as a result of the chronic lack of consistency in home care provision (recommendation 7). With visits at irregular times and with different care workers at each call, older people with dementia are most at risk as it is vital they receive consistent care tailored to their individual needs. The status of social care work must be raised and better dementia training given to staff, to ease the frequency of staff turnover and, therefore, improve the quality of service given to older people with dementia. It is clear that better and more personalised support in the community together with other preventative measures could serve to reduce early need to move into a care home or a hospital, less need for medication and therefore, improve quality of life while reducing the costs involved.

Short breaks for people with dementia and their family carers (recommendation 8) are becoming more and more significant as pressures on families and carers increase when local authorities only provide care to those with 'substantial' or 'critical' needs. Short break (or respite care) provision must be flexible and personalised to suit the individual needs of the older person and their family. This is especially important for older people with dementia. There must be a move away from a 'one size fits all' approach to commissioning for short breaks provision. As is highlighted in our policy paper: *A New Strategy for Carers: better support for family and carers of older people, 2007,* emergency support must also be available to provide timely and appropriate support as soon as possible if informal care breaks down due, for example, to the carer's own health failing.

In spite of a formal diagnosis of dementia, there is much that can be done to improve the older people's situation, and encourage or maintain a standard of independence. However, many health and social care professionals do not recognise this. Stamping out discrimination is crucial in terms of access to intermediate care, rehabilitation,

occupational therapy assessments and palliative care for older people with dementia (recommendation 10).

According to Dementia UK, 64% of people in care homes have dementia, which often goes undiagnosed. Recommendation 11 is of paramount importance in ensuring that older people in care homes receive suitable and specialist care and support to meet all of their complex needs in full. At present, care homes are often isolated from the services available in the local community, and within care homes, older people with dementia are the most isolated and unable to communicate their needs. Ensuring that specialist mental health services and community dentists, pharmacists, geriatricians and optometry as well as GPs are commissioned to go into care homes (and actually do so) will be a real step towards opening up care homes to the outside world and in recognising the needs of an older person with dementia in the round.

It should become a requirement of the new Care Quality Commission that all care homes are registered as able to meet the needs of older people with dementia, unless they can provide a specific reason not to (recommendation 12), so the assumption of a move to a care home is one of a lifetime stay rather than the threat of constant moves at the very point where the older people's needs have increased and become more vulnerable to change.

Question 11: Is there anything that has been missed which would help to improve the quality of care for people with dementia and their families?

More support is needed for older people with dementia, their families and carers to raise concerns and make complaints about standards of care if the quality of care is to improve. The fear and confusion surrounding the idea of making a complaint must be removed. It impacts especially on those older people with the most complex needs or a dual-diagnosis, who have services jointly funded by both health and social care. In these situations, it is often difficult to clarify who is responsible for the package of care provided when it might involve a combination of health and social care staff. It can be

unclear for older people, their families and carers to whom they should direct their concerns and whom is ultimately responsible for each part of their care as the distinction between health and social care can be so arbitrary. Moves towards amalgamating the two procedures into one simplified and unified approach is a positive step, but there is still a lot of work that needs to be done to ensure the voices and concerns of older people with dementia, their families and carers are heard.

Question 12: What more could be done in acute care, home care and care homes?
While the policy move is towards supporting older people with dementia to remain living interdependently at home for as long as possible (as it should be), it must also be recognised that for some older people with dementia, there will come a time when this will no longer be possible and actually the best way of meeting their needs would be a move to a care home. Therefore, the number and capacity of care homes that can provide dementia care must increase to match the predictions of a population 'timebomb'.

As is practised in Anchor Trust, it is important to have a dementia care team across care homes, home care and in acute care settings that will champion specialist dementia care training and will be one point of contact for staff needing ongoing advice and support about specific practical situations.

Access to independent mental capacity advocacy must be promoted and facilitated whenever possible for older people with dementia who do not have support from family, and independent advocacy must be better funded and promoted in general. Advocacy provision is patchy and under resourced across the UK, despite the best efforts of many charities and voluntary organisations like ours who are involved in raising its profile. In particular, there is a gap in advocacy support for those older people who self-fund their care and/or live in a care home. Recognition must be made of the vulnerability of self-funding residents, who have to manage without support from social services, especially those with dementia. Extra emphasis must be placed

on private care home providers to ensure that these residents and their families are supported to access independent advocacy and advice.

Question 13: What should be done to make the agenda of the personalisation of care including individual budgets work for people with dementia and their family carers?

While currently undermined by rationing, the personalisation agenda must work to promote more innovative approaches as the first option for older people with dementia rather than simply writing a prescription for drug treatments. A more holistic view of an older person should be promoted that encourages access to support, services or activities that meet the older person's social, learning and leisure needs as well as their care and medical needs.

As is called for in *Care Contradictions 2008*, councils must be brave and challenge existing practices with innovative new ways forward in order to ensure that the transformation agenda does not remain simply rhetoric, but makes a meaningful difference to the lives of older people, their families and carers.

Question 14: What can you or your organisation do to help implement these recommendations?

Counsel and Care will continue to support older people with dementia, their families and carers to access good quality care within any community care setting, and to encourage them to raise a complaint or access independent advocacy if they have concerns.

We will also lobby government and local councils to ensure that the personalisation agenda becomes a reality for all older people, including those with dementia or who sometimes lack mental capacity, and to ensure that they are able to 'live their lives as they wish, maintaining independence, well-being and dignity, while making use of high-quality and accessible services' (*Care Contradictions 2008*).

Delivering the National Dementia Strategy

- **Recommendation 13: Clear information on the delivery of the National Dementia Strategy**
- **Recommendation 14: A clear picture of research evidence and needs**
- **Recommendation 15: Effective support for implementation**

Question 15: Are these outcomes, recommendations and the suggested means of achieving them the right ones?

Counsel and Care agrees with recommendation 13, in particular, that information on the delivery should be easily obtainable and disseminated out to all relevant parties. It should be made clear who is responsible at a national level and what action can be taken if the strategy is not being delivered appropriately at local level or in line with previously established timescales.

While current research on dementia is strong (recommendation 14), it is important a strategic picture of where we are now is currently taken so that research work is not duplicated and that more research is carried out in areas where there are 'gaps' in knowledge, such as prevention and early onset of dementia. A co-ordinated approach would be the most effective way of doing this, bringing together the expertise of organisations, scientists and funders under one overarching representative research body.

Question 16: Is there anything that has been missed to help us deliver the National Dementia Strategy?

Such an ambitious vision for high quality care must be backed with a fitting amount of funding if it is to encourage meaningful change on the ground in the long-term for older people with dementia receiving care and support (recommendation 15).

Currently there is a high level of confusion about funding for long-term care in general, and more so for older people with a medical condition, such as dementia. Counsel and Care has called in *A Charter for Change* for a new model of care which must ensure 'simpler', 'fairer' and 'transparent' access to and provision of 'flexible'

services for older people, their families and their carers. In particular, the Alzheimer's Society has called for the 'dementia tax' to be abolished, and for all older people with dementia to receive fully-funded NHS continuing healthcare. The system is very confusing for people with neurological conditions whose needs are not easy to deconstruct into health and social care components. It is vital that as the Green Paper consultations with older people, their families and carers occur, a new and more consistent way of allocating resources is drawn up in line with long-awaited social care reform.

Question 17: What are your priorities for implementation? What can and should be done first?

Counsel and Care considers the comprehensive package of high quality information to be the key priority for implementation in the first year after publication of the strategy, if also extended to include access to good quality and *independent* advice, support and advocacy for older people, their families and carers.

The dementia care advisor role is also of utmost importance and, therefore, after its role is clarified it should be implemented at local level. However, this must be done with the required practical resources and funding to ensure that the role is sustainable over the long-term.

Training is central to transforming the quality of care and should also be a key priority for implementation.

Question 18: What should the timetable for implementation be?

There is no time for delay in implementation of such a vital strategy with the potential to totally transform the lived experiences of older people, their families and carers. Public awareness raising and the introduction of the information package could relatively quickly ensure real impact is felt amongst the general public and those using services.

However, this is also a long-term strategy aiming to provide full-scale transformation and permanent change. Throughout the five-year plan it is important that good practice is shared and monitoring undertaken to establish whether targets have been achieved and consideration given to maintaining the changes in the future.

Question 19: What can your organisation do to help implement these recommendations?
Counsel and Care will continue with its lobbying and campaigning work with government with the forthcoming green paper in Spring 2009 to ensure that all older people, including those with dementia, their families and carers get the best care and support, backed up by appropriate resources and the funding they deserve. We are also keen to be involved and feed our knowledge where appropriate into the development of a national dementia research strategy.

Question 20: Does this draft strategy fully address issues of equality and diversity, and the needs of particular groups?
Counsel and Care recognises that dementia does not discriminate, and it is a disease that affects younger people as well as older people, and individuals suffering with the disease come from all cultural and ethnic backgrounds. People often have dementia in addition to another complex condition, such as people with learning disabilities or sight and hearing problems or a chronic medical condition. This must be recognised when the strategy is implemented at local level to ensure that there is equal access to services for all.

Counsel and Care
Twyman House
16 Bonny Street
London
NW1 9PG
www.counselandcare.org.uk

For more information or clarification about anything included in this response, please contact Anna Passingham at anna.passingham@counselandcare.org.uk or 020 7241 8523.