



*The dementia category in registration of care homes in Wales:
Report on a consultation on its discontinuation*

*Undertaken for Care and Social Services Inspectorate Wales
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Introduction

In Wales, residential settings which provide care for people diagnosed with a dementia are required to be registered within the ‘dementia category’ by the Care and Social Services Inspectorate Wales (CSSIW). A number of issues that have been raised concerning this practice prompted consideration of whether the use of the dementia category should be discontinued. To inform this decision, CSSIW commissioned the Dementia Services Development Centre (DSDC) Wales to undertake a brief consultation (in October and November 2011) with stakeholders and other relevant parties, including a sample of people with dementia, family caregivers, representative organisations, care home providers, Directors of Social Services, clinicians, policy makers, and members of the Wales Dementia Group (see Appendix 1 for a full listing).

Concerns regarding the dementia category

There are approximately 40,000 people living with dementia in Wales, according to the authoritative Dementia UK report (2007). This number is expected to increase by nearly a third by the year 2021. Dementia is the strongest determinant of entry into residential care in older people, and studies suggest that around two thirds of residents living in a care home have some form of dementia. However, only one third of care home places in Wales are registered within the dementia category, and so it is self-evident that there are likely to be as many people with dementia in care home places in Wales outside the dementia category as there are within it.

The emphasis on a diagnosis of dementia, rather than the person’s specific needs has led to concerns regarding the creation of a perverse incentive not to diagnose dementia in existing care home residents, in case the person is then required to move to a place with the dementia category, even though their needs may be met satisfactorily in their current placement. Avoidance of a diagnosis in turn may also mean the person does not receive dementia-related treatments.

Given the increasing prevalence of dementia, it has been suggested for some time that there is a need to mainstream the provision of dementia care, as the core business of all care homes for older people. ‘Restricting the recognition of dementia to a minority of homes is a

dangerous fiction which does little for people in residential and nursing care' (Macdonald & Denning, 2002).

The current practice does not appear to have a legal basis, and inconsistency is acknowledged in that CSSIW assume homes registered for nursing are also able to provide for people with dementia. As the needs of people with dementia vary widely, a categorisation based on dementia diagnosis is not informative regarding the capability of a home to provide good quality care for any specific person with dementia.

The purpose of this consultation is to make recommendations regarding the impact, and potential risks and benefits of discontinuing the use of the 'dementia category' within Wales, and to remove the requirement that anyone with a diagnosis of dementia must be placed in a care home registered to provide specialist care for this client group. In making recommendations, reference will also be made to the situation in England, where specific registration categories are no longer used.

Method

A brief survey form (Appendix 2 and 3) was designed and made available on-line through 'Survey Monkey', and invitations to respond were circulated to relevant individuals and groups. Care Forum Wales made the link available to their members on their web-site, and responses were received from the Alzheimer's Society, the Care Quality Commission (CQC) and the English Community Care Association which enabled perspectives from the experience in England to be included. The views of people with dementia and family care-givers were sought in a small focus group (n=8) in North Wales. Family care-givers were also invited to respond through a meeting for relatives of residents in care homes in one local authority. In total, 129 responses have been received to the survey, with the great majority having been completed on-line. Questions were open-ended inviting free text responses, with opportunity for providing additional comments if desired.

Potential benefits of discontinuing the 'dementia category'

People with dementia able to remain in existing care home

Overall, respondents were clear that there were a number of benefits of discontinuing the use of the 'dementia category'. First, existing care home residents would be able to remain in their current home upon diagnosis and not be required to move to a dementia registered home. Respondents recognised that current practice did mean that some care home residents who had received a formal diagnosis were in fact required to move, and this was a distressing experience for both the person with dementia and their family. Related to this issue is the fact

that many care home residents with dementia are currently being cared for appropriately within non-dementia specialist homes. Respondents felt that if the existing care home continues to meet the needs of the person with dementia, then a move based solely upon a diagnosis would be unnecessary and inappropriate. For example, “One individual was required to move purely due to a change in diagnosis without any particular evidence of any change in need” (Consultant Geriatrician). It was felt that not only did this practice defy person-centred care, but also encouraged a situation whereby health professionals avoid giving a diagnosis of ‘dementia’ due to the risk the diagnosis poses to a person’s placement. One respondent stated “I see residents every day in care homes who have dementia, which I label as “cognitive impairment” to support the home continuing care for them. They are deprived of other treatments e.g. Anti-cholinesterases (*sic*) as a result. This is wrong” (Consultant Geriatrician). Another health professional stated that “Placements should be needs based, not diagnosis based” (Senior Practitioner Social Worker).

Care home proprietors also stated that one of the main advantages of removing the categorisation was that residents would be able to remain in their existing home if they received a diagnosis of dementia. Once again, there was recognition that non-dementia specialist homes can meet the needs of people with dementia. For example “residents would not have to be moved to an alternative home when the home is coping with their dementia” (Care Home Manager). Additionally, one care home manager noted, “One big advantage [of removing categorisation] is that more residents would be properly diagnosed”.

Mainstreaming dementia care

The Alzheimer’s Society stated that “dementia care is a key task of the care home sector generally” and “...removing the dementia category could be one way in which to mainstream the provision of dementia care in care homes”. Given the increasing prevalence of dementia and current statistics relating to the numbers of care home residents with dementia, one respondent suggested that “All care homes should have the capabilities to meet the needs of a person with dementia...it is unfortunate at the moment that the regulations...promotes the need for people to move as their care needs change” (Director of Social Care, Wales). Furthermore “...all care settings and staff should be able to care for clients with dementia. Categories are very artificial and not in the interests of clients” (Consultant Psychiatrist). Although many respondents believe the mainstreaming of dementia care to be a positive step, it is based on the proviso that care home staff have access to appropriate dementia care training. For example, “...the general care home sector needs to be trained and supported to meet the needs of people with dementia” (Alzheimer’s Society). The Alzheimer’s Society noted that the recently published Welsh Assembly Government Dementia Vision and Action

Plans have a role to play in increasing the availability of training. It also stated that removing the category would be one way in which to improve the diagnosis rates in Wales.

Choice and flexibility when choosing a care home

Removing the 'dementia category' would allow more choice of care homes for people with dementia. One health professional noted "The dementia category has been disruptive and based upon service availability rather than a person's need". This issue of choice and flexibility when choosing a care home is an issue particularly pertinent to people living in rural Wales where an out of county placement may be required upon receiving a diagnosis of dementia. One health care professional summed up the current situation by stating that "...currently people living with dementia have a stark choice: either a formal diagnosis and the support from services that goes with that but limited choice of homes, or no diagnosis and the preferred choice of home but no support from services". Care home proprietors echoed the statements made by professional respondents by stating that one of the potential advantages of removing the 'dementia category' is "...people who have a diagnosis of dementia would have more choice of where they would like to live as currently...as soon as a diagnosis is made...we are restricted about the care we can offer". Another respondent echoed this view by stating that "diagnosis of dementia is essential to promote best management, but it should not be a barrier to service provision" (Clinical Psychologist).

In England, one of the main advantages following the removal of the dementia registration category is "the ability for providers to be more flexible and accessible in how they design and deliver their service, and who they can offer and provide their services to" (CQC). Furthermore, the CQC noted that the removal of the 'dementia category' supports and encourages care homes to provide a service to any individual who they feel able to support and care for, and the "new system is far more predicated on person-centred care". As the CQC states, feedback on the new system has been "positive...the system seems more simple and less burdensome and allows more flexibility in service provision". Additionally, they noted "owing to the UK's changing demographics, we increasingly expect all services we regulate to be working, at least to some extent, with people living with dementia, and therefore, the use of the dementia category has certainly lost a lot of its usefulness and purpose in today's society".

Potential risks of discontinuing the 'dementia category'

Lack of adequate staff training

Potential risks associated with removing the category included the potential for compromised quality of care by staff who may not have received adequate training in providing care for

people with dementia. For example, “People caring for those with dementia require specialist training. I fear that removal will result in untrained staff caring for people with dementia”. Furthermore, there were concerns regarding potential loss of specialisation in dementia care. Many respondents saw dementia care as more specialist than non-dementia care, often requiring a higher level of training. This specialisation is reflected in the payment from councils of higher fees for dementia-registered homes. One respondent noted, “if you remove this category you may find there is little incentive for people to develop specialist dementia services, and also less incentive for people to ensure staff have the relevant dementia training” (Director of Social Care, Wales). A care home proprietor also noted “I am concerned this is an attempt to no longer recognise the specialist care we currently provide and pay less funds, with a lack of specialism among staff”. The Alzheimer’s Society also noted concerns regarding lack of appropriate staff training if the ‘dementia category’ was to be discontinued: “...people with dementia will be in care homes where staff have not got the skills to provide high quality care”. On the other hand, one respondent stated that “training and ongoing care should be part of CSSIW quality monitoring...this would counter any potential for expertise to be lost if homes lose their dementia categorisation. Dementia is in all care settings and we need accommodation, training, quality control and specialist support that reflects this” (Consultant Psychiatrist). Focus group members agreed: “Training is essential”.

Lack of guidance when choosing a care home

Concerns were raised that removing the ‘dementia category’ may make it more difficult to identify care homes which can provide appropriate care and support for people with dementia. For example, “Choosing a care home is a difficult decision and it is often made at a time of crisis...information needs to be easy to access and understand. In this respect, the dementia category can be helpful in quickly identifying care homes that are appropriate for a person with dementia” (Care Home Manager). The Alzheimer’s Society state that if the category is removed, then “...there needs to be consideration of the best way of communicating information about care homes and supporting people to make informed choices about their care”.

In England, the CQC have noted that the only negative consequence of the removal of the category has been their ability to search for detailed information specifically related to services that work with people with dementia. The current system requires providers to send CQC a Statement of Purpose when they register whereby they accurately describe the type of service they will provide. This information is available for the public and professionals to access on a website. Whilst the new system allows service providers to state the type of service they will provide, the CQC does recognise that this information may on occasions be

out of date. Furthermore, they stated “there may still be some clarity of communication required however, to ensure that the public and professionals are aware that CQC no longer registers the care home to provide such specific services, and this information is based on the providers self description”.

During our consultation, we sought respondent’s views on using a care home’s ‘Statement of Purpose’ (SoP) when deciding whether a home can meet the needs of a person with dementia. Whilst some supported the use of the SoP and felt it is a “much better idea than classification”, others noted concerns regarding compliance with, and monitoring of the SoP. For example, “As long as the home actually delivers the service that is identified in the statement of purpose this should be acceptable although it may raise issues of compliance and monitoring”. In support of this statement, another health professional noted they “would support the use of the SoP if there is adequate enforcement powers to support it”. One respondent felt that using the SoP would “... add clarity about the service provided. It would encourage providers to give careful consideration to explaining what they are able to achieve” (Director of Social Services, Wales). Another Social Services Department lead suggested that compliance could be addressed through existing mechanisms: “There remains a responsibility on the commissioning authority to safeguard the individual’s wellbeing, through contracts, reviews etc.”, although this is more problematic for self-funding residents.

Alternatively, other respondents felt that “A Statement Of Purpose wouldn't necessarily reassure that a person’s needs can be met”. Furthermore, one respondent felt that “these statements are generic, all encompassing - they are not regulated, and frankly unhelpful”. One care home manager felt that using the SoP would be “inadequate - the needs of an individual with dementia with vary over time - each home with an interest in providing dementia care should be encouraged to advertise this with registration/qualifications rather than general statements”. Commensurate with this view, one respondent stated “the advantage of retaining the dementia registration is that there is a governing body which tests compliance against the regulated services, which gives assurances to citizens. A SoP would not give the same assurances”.

Care home proprietors responses were equally mixed with some stating that the SoP can adequately reflect the home’s capability of providing care for people with dementia. For example, “each home's statement of purpose will provide information on the home’s capability on providing care for dementia patients and the level of dementia training given to staff. We totally agree that the registration categorization regarding dementia is removed”. The role of the CSSIW in verifying the SoP was raised: “this would help provided that it

[SoP] accurately reflects what the home offers and is verified by CSSIW”. On the other hand, respondents raised concerns regarding the accessibility of the SoP: “People find it difficult enough to discover the correct home with the present guidance. With the classification 'hidden' in a statement of purpose it would be far more difficult” (Care Home Proprietor). The Alzheimer’s Society echoed this concern by stating that “In England...[we] are concerned that people don’t have the appropriate information to make informed choices about care homes...There...needs to be easily available and understandable information about how the care home is inspected and regulated”. Focus group members again wanted to be able to know that staff had proper training in dementia care. A response from England stated “I believe that there is little understanding of how you check whether or not a statement of purpose is being delivered. If you go down this route there needs to be a public awareness campaign about what to look for in care services and how to check that the statement of purpose is being delivered upon”.

A need for specialist units

A number of respondents were clearly concerned that discontinuing the dementia category would lead to one, uniform type of provision, where the needs of people without dementia would not be met: “Residential service users without dementia would be affected due to challenging behaviour sometimes shown by dementia residents. This can be very distressing and frightening to others at times. Also staff time would be more focussed on dementia service users to keep them safe and stimulated and to avoid challenging behaviour” (Care home manager). In similar vein, another care home manager expressed her concerns thus: “It is a specialism and if I had full capacity and needed physical care I would not necessarily want to be close to people that couldn’t communicate or act in a way that may annoy or frighten me”. Focus group participants commented that it can be helpful for people with dementia to mix with people without.

Other professionals emphasised the need for specialism to meet the needs of a sub-group of people with dementia: “for people who have a high level of dementia support needs...a different environment is required” (Social Services Director). “There will always be some people with dementia who require highly specialist dementia care due to complex and severe behavioural and psychological symptoms (BPSD)” (Consultant Psychiatrist). Focus group participants thought specialist care homes should have extra staff, and that they could be helpful in providing a sense of safety and reassurance. A number of examples were cited by respondents where a move to a dementia care home had been beneficial for a person with dementia, as the new home was better equipped to meet their needs.

Conclusions and recommendations

1. The proposal to discontinue CSSIW'S requirement that anyone with a diagnosis of dementia must automatically be placed in a care home registered for dementia would command wide-spread support, although there are concerns regarding follow-on effects from changes to the status quo. It is recommended that these concerns be addressed, but that retaining the dementia diagnosis category is not an appropriate way to do this.

2. The proposal to discontinue the use of the dementia category completely and instead only use conditions of registration to exclude care homes from caring for people with dementia where they have proved incompetent to do so and rely on homes setting out who they care for and how this is achieved in the home's Statement of Purpose, has more mixed support, with care home providers and local authorities having some reservations. There is concern regarding whether the Statement of Purpose can be used effectively and concern that there will be dilution of specialist dementia care and a reduction in standards. A number of stakeholders would want CSSIW to verify the Statement of Purpose and provide assurance to the public. One option would be to consider a needs-led dementia categorisation, perhaps registering those homes capable of addressing the needs of people with dementia whose behaviour is challenging or who are experiencing high levels of distress. Indeed, some appeared to be viewing this as the de facto status quo. However, this option would run the risk of creating a new set of unintended effects, given the fluid nature of such needs and the influence of the care environment on their development and maintenance. It is recommended that the proposal to discontinue the dementia category entirely be pursued, but great care be taken to ensure that the issues raised are addressed in the new approach.

3. In order to address the concerns raised regarding both proposals (1) and (2), the following recommendations are made:
 - a) The Statement of Purpose should include a number of standard sections, so that it is possible to identify readily those homes stating that they are able to address the needs of particular sub-groups of people with dementia e.g. 'people with dementia who are very active'; 'people with dementia requiring palliative care'; 'people with dementia with behaviour that challenges' and so on. The Statement of Purpose should be made available to the public through the internet, clearly flagged as a self-rated document.
 - b) The Statement of Purpose should set out clearly the training and development programme for staff in relation to dementia care, including details of courses, qualifications etc.

- c) The Statement of Purpose should set out clearly how the care home environment is geared to the needs of its residents, specifically including those with dementia, using environmental audit tools to justify the case made.
- d) Where local authorities and health boards are involved in commissioning or funding a resident or places in care homes, monitoring and verifying the Statement of Purpose should form part of the agreement with the care home.
- e) CSSIW should continue to develop means to ensure that individuals' needs are being met within each care home, with greater use of observational tools and other methods which enable the experience of people with dementia to be reflected more fully.

Appendix 1.

Complete listing of stakeholders and other parties responding to the consultation

*Alzheimer's Society

Care Forum Wales

Directors of Adult Social Services in Wales

Royal College of Psychiatrists Old Age Faculty Wales

British Psychological Society 'Psychology Specialists working with Older People' Wales

Clinicians and mental health professionals

Social workers

Continuing Health Care assessors

Dementia care Advisors / coordinators

Members of the Wales Dementia Steering Group

Care Home providers (managers and proprietors) – Social Services and independent sector

People with a dementia and family caregivers

Commissioners of social care services

*The Care Quality Commission (CQC)

English Community Care Association

National Care Forum

* Response received on behalf of organisation; other organisations listed circulated the link to their members

Appendix 2.

Professionals survey



Consultation on the use of the ‘dementia’ category in care homes in Wales

- Currently in Wales, the Care and Social Services Inspectorate (CSSIW), the regulating body for adult social care, requires a care home to have gained registration within the ‘dementia category’ if they provide care for people with a dementia.
- But in reality it is likely that many people with dementia are being cared for in places without the dementia registration. Current estimates suggest that two thirds of care home residents have a dementia, but only a third of care home beds are registered for the dementia category.
- There is an argument that the current practice offers a disincentive to diagnose dementia in those who are already resident in a care home, in case they are required to move to a home registered within the dementia category.
- Others argue that a dementia diagnosis in itself says little about a person’s needs, and it is ensuring that the person’s needs are met which should be the focus.
- In England, categories of registration are no longer used. Instead, people are encouraged to refer to the care home’s ‘statement of purpose’ when deciding whether a care home can meet the needs of a person with dementia.

These and related issues have prompted the CSSIW to commission DSDC Wales to undertake a consultation in relation to the potential impact of making changes to the categorisation of care homes in relation to dementia care in Wales. We would be most grateful for your views on the current situation, which will inform our recommendations concerning the potential impact of discontinuing the use of the ‘dementia category’.

We would be extremely grateful if you could answer the questions below within the next two weeks. All answers will remain confidential.

Please complete this section if you are responding in a professional capacity:

Name and/or e-mail address (optional)

What is your occupation / position?

Please state the name of your organisation

Please indicate if you own / manage / work in a care home(s) ? Yes No

Is your experience in Wales? England? Both?

1. Currently in Wales, the Care and Social Services Inspectorate (CSSIW) requires a care home to have gained registration within the ‘dementia category’ if they provide care for people with dementia. What do you think would be the advantages of removing the current ‘dementia’ categorisation?
2. What **negative consequences**, if any, do you envisage if the ‘dementia’ categorisation is removed?
3. In England, categories of registration are no longer used. Instead, people are encouraged to refer to the care home’s ‘statement of purpose’ when deciding whether a care home can meet the needs of a person with dementia. What are your views on the use of the **statement of purpose** as the indicator of the capability of the home to provide care for people with dementia?
4. What are your views on the current situation in Wales where when a person is diagnosed with dementia they may be required to move to a care home with the dementia category?
5. Do you have experience of older people being **required to move** to a different care home, following a diagnosis of dementia? If so, what were the consequences?
6. If you were helping someone to **find a care home** for a person with dementia, do you think the ‘dementia’ categorisation would be helpful?
7. Please add any **other comments** you would like to make not covered previously.

Thank you very much for taking the time to complete this questionnaire.

Appendix 3.

Carers (and people with dementia) survey



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- Others argue that a dementia diagnosis in itself says little about a person’s needs, and it is ensuring that the person’s needs are met which should be the focus.
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These and related issues have prompted the CSSIW to commission DSDC Wales to undertake a consultation in relation to the potential impact of making changes to the categorisation of care homes in relation to dementia care in Wales. We would be most grateful for your views on the current situation, which will inform our recommendations concerning the potential impact of discontinuing the use of the ‘dementia category’.

We would be extremely grateful if you could answer the questions below within the next two weeks. All answers will remain confidential.

We would be extremely grateful if you could complete this questionnaire and return in the FREEPOST envelope. Or, if you would prefer, you can complete the questionnaire on-line by following this link:

<http://www.surveymonkey.com/s/NTHL7LV> (English only on-line). All answers will remain confidential.

1. Are you a carer of a person with a dementia?

Yes

No

2. Have you been diagnosed with a dementia?

Yes

No

3. Are you currently living in a care home in Wales?

Yes

No

4. What do you think would be the **advantages** of removing the current 'dementia' categorisation?

5. What **negative consequences**, if any, do you envisage if the 'dementia' categorisation is removed?

6. What are your views on the use of the **statement of purpose** as the indicator of the capability of the home to provide care for people with dementia?

7. What are your views on the current situation in Wales where when a person is diagnosed with dementia they may be required to move to a care home with the dementia category?

8. Do you have experience of older people being **required to move** to a different care home, following a diagnosis of dementia? If so, what were the consequences?

9. If you were helping someone to **find a care home** for a person with dementia, do you think the 'dementia' categorisation would be helpful?

10. Please add any **other comments** you would like to make not covered previously.

Thank you very much for taking the time to complete this questionnaire.