National Institute for Health and Care Excellence

Mental wellbeing of older people in residential care
Quality standard topic engagement comments table

Name	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Karin Tancock	College of Occupational Therapists	Key area for quality improvement 1 **Mental wellbeing of people with dementia.**	Call for Action by NHS Innovations and Improvements to reduce use of anti-psychotic medication (March 2012) developed in response to over reliance on and misuse of anti – psychotic medication. National Minimum Standards for Care Homes for Older People (DH, 2003) Standard 7- Service User Plan. Outcome:the service user's health, personal and social care needs are set out in an individual plan of care.	National Call to Action: Reduction in the use of anti psychotic medication. Care plans are expected to outline strategies and approaches to working with residents with dementia when they appear agitated or distressed. There is limited access to expertise to assess and advice staff, family and friends on communication and understanding the experience of the person with dementia.	CQC Care Update Issue 2: March 2013 identified 1 in 10 care homes are not providing a good quality of care.
Karin Tancock	College of Occupational Therapists	Key area for quality improvement 2 **Opportunities to engage in daily activities**	National Minimum Standards for Care Homes for Older People (DH, 2003) Standard 12- Social Contact and activities.	Outcome to standard 12 in the care home standards states: The routines of daily living and activities made available are flexible and varied to suit a person's interests and needs. Service users have the opportunity to exercise choice. Standard 13. Community Contact. Service users are supported to maintain contact with family and friends.	Even small amounts of mental, physical and social activity matter when accumulated. It is therefore important for older adults to participate in mentally, socially and physically stimulating activities as this may postpone the onset of dementia *Fratiglioni L, Winblad B, Struass E (2007) Prevention of Alzheimer's disease and dementia: major findings from the Kungsholmen project. Physiology and Behaviour, 92(1-2), 98-104.* Residents were more likely to occupy their time in the main sitting room passively, rather than in interactive occupation and social engagement. The nursing home residents with dementia spent approximately 70% of their daily time in the main sitting room areas in states of

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					occupational disengagement." Morgan-Brown, M; Ormerod, M; Newton, R; Manley D,(2011) The British Journal of Occupational Therapy, 74, 5, , pp. 217-225(9) London: College of Occupational Therapists
Karin Tancock	College of Occupational Therapists	Key area for quality improvement 3 **Equality of access to health care for people with dementia living in care homes.**	The British Geriatrics Society (2011) recommends care home residents have the same right to healthcare as people living in the community. This includes access to occupational therapists, AHPs and community nursing services. *British Geriatric Society (2011) An Inquiry into the Quality of Healthcare Support for Older People in Care Homes: A Call for Leadership, Partnership and Improvement. London: British Geriatrics Society.*	People move into residential or nursing care as they have complex needs. Typically a resident has experienced bereavement and loss; frailty related to older age and has one or more long-term conditions. The Alzheimer's Society (2013) report that 80% of residents have dementia or a cognitive impairment. Despite this, a coordinated model of multidisciplinary care has not been developed and many care home residents have limited access to suitable NHS primary and secondary healthcare Alzheimer's Society (2013) Low Expectations; Attitudes on choice, care and community for people with dementia in care homes. London. Alzheimer's Society. Available at: www.alzheimers.org.uk/lowexpectations Accessed 12.03.13	Occupational therapists provide appropriate exercise or other activities that are graded to an individual's capabilities to increase their quality of life, preserve their identity and provide them with a positive emotional outlet. *National Institute for Health and Clinical Excellence (2008) Occupational therapy interventions and physical activity interventions to promote the mental wellbeing of older people in primary care and residential care. London: NICE.*

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Samantha Sharp	Alzheimer's Society	Improvement in the quality of dementia care through developing leadership in this area.	The National Dementia Strategy for England recommends the identification of a senior staff member within the care home to take the lead for quality improvement in dementia care in the home. They are required to lead the development of a local strategy for the management and care for people with dementia in the care home. The NICE dementia quality standard already specifies the need for staff training in dementia, but research shows staff training must be supported by ongoing support, supervision and management if it is to improve the quality of life of residents. A 'Dementia Champion' within the home can ensure staff are supported to promote mental wellbeing amongst people with dementia.	The quality of dementia care within some care homes is still poor. A number of reports have described the unacceptable variations in the quality of dementia care in care homes (CSCI, 2008, Alzheimer's Society, 2008 and 2013). CSCI found that leadership, ethos of the home, staff training, support and development are the crucial factors in supporting good practice, therefore they are key areas in which to focus in order to improve quality of care.	Information from CQC inspections. Potentially information from monitoring of the Dementia Care and Support Compact
Samantha Sharp	Alzheimer's Society	Access to in-reach specialist older people's mental health teams	Access to in-reach specialist older people's mental health teams is recommended in the National Dementia Strategy for England. Everybody's Business and the NICE Guideline on dementia also make it clear that care homes should receive good support from external services. This improves care by enabling staff training, advice on specific problems, development of non-pharmacological approaches for residents with behavioural symptoms and monitoring and review of the use of	The NDSE identified that current input from mental health services is generally on an ad-hoc basis or reactive with referrals at times of crisis. An Alzheimer's Society survey (2007) informing its report 'Home from Home' found one third of care home managers reported no support or very limited support from the local older people's mental health service. One quarter of care home managers listed	

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			antipsychotic drugs. Ballard *et al.* (2007) found a psychiatric liaison service significantly reduced the use of potentially harmful neuroleptic drugs, reduced GP contacts and led to a three-fold lower number of days in psychiatric inpatient facilities. The discontinuation of neuroleptics in 40% of people taking them did not lead to an exacerbation of behavioural or psychiatric symptoms.	accessing advice from external services as one of the top three challenges in providing good dementia care. The literature review to inform My Home Life programme found that specialist mental health services were not widely available to care homes (Heath, 2007).	
Samantha Sharp	Alzheimer's Society	Participation in activities and meaningful engagement	Opportunities for occupation and pleasure in care homes significantly affect outcomes for residents. Those people who obtain little pleasure from things they do in the home are more likely to die and more likely to be depressed after nine months (Mozley, Sutcliffe, Bagley *et al.*, 2004). Inactivity and low levels of engagement also contribute to loss of physical function, social isolation, behavioural symptoms and poor quality of life (Mor, Branco, Fleishman *et al.*, 1995; Alessi, Yoon, Schnelle *et al.*, 1999).	The Alzheimer's Society report *Low Expectations* (2013) found only 44% of families surveyed felt that opportunities for activities in the care home were good. People with severe dementia are at particular risk of exclusion from activities and engagement. One study found that only 6.5% of residents at five care homes received appropriate activities despite high attendance at activity sessions (Buettner and Fitzsimmons, 2003).	Information from CQC inspections. Potentially information from monitoring of the Dementia Care and Support Compact
Samantha Sharp	Alzheimer's Society	Assessment and treatment of depression in people with dementia	At least 80% of care homes residents have dementia (Alzheimer's Society, 2013) and 50% of all residents have depressive disorders that would warrant intervention (NICE, 2007). The NICE Clinical Guideline on Dementia recommends people with dementia should be assessed and monitored for depression	People living in care homes seem to be particularly at risk of depression. Anxiety in people living in care homes has been linked to unmet needs, including a lack of daytime activities and a lack of company. Depression and anxiety are commonly associated with dementia (Ballard et al, 1996) but can	

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			and/or anxiety.	be difficult to diagnose, creating a risk of under-recognition and under-treatment.	
Cathy Yelf	Macular Society	Psychological impact of sight loss	The incidence of age-related sight loss conditions such as macular degeneration is rising as the population ages. Age-related macular degeneration (AMD) is the biggest cause of sight loss in the UK. More than 500,000 people have late stage AMD and that is expected to rise to 650,000 by 2020. While only 1 in 2000 people has AMD at age 60, 1 in 5 will be affected at age 90. Many elderly residents of residential care homes will have AMD or another age-related sight loss condition.	Both the incidence and impact of sight loss can be underestimated. As a result too little practical or psychological support may be given. The incidence of sight loss in residents of care homes is poorly researched but RNIB have estimated that half of all residents could be affected. While is it not clear that residents of care homes receive less support than people not in care homes, there is evidence that, in general, people diagnosed with sight loss do not receive the psychological support they need.	• The estimated prevalence and incidence of late stage age related macular degeneration in the UK: Christopher G Owen,1 Zakariya Jarrar,1 Richard Wormald,2,3 Derek G Cook,1 Astrid E Fletcher,2 Alicja R Rudnicka1 2012 May;96(5):752-6. doi: 10.1136/bjophthalmol-2011-301109. Epub 2012 Feb 13. • Undetected sight loss in care homes: an evidence review. Jessica Watson and Sally-Marie Bamford, International Longevity Centre – UK, July 2012. This found that awareness of sight loss was patchy among staff of care homes and made a number of recommendations on improving the diagnosis and response to sight loss in residents of care homes. http://www.ilcuk.org.uk/files/Undetected_sight_loss_in_care_homes.pdf • 70% of newly-diagnosed blind and partially sighted people wanted someone to talk to about their fears and concerns but only 19% were offered this opportunity by their eye clinic (Patients Talking 2, 2001) • Nearly 1 in 5 (17%) of blind and partially sighted people surveyed received no help or information in the eye clinic other than medical diagnosis and treatment. This rises to 1 in 3 (32%) for working age adults (Network 1000 Wave 2, 2008) • Visual impairment is associated with a higher than normal risk of depression. Branch et al (1989), Campbell et al (1999), Carabalese at al

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					(1993), Wahl, Oswald et al (1999) as well as Wahl, Schilling et al (1999). The Carabalese study found that persons with vision impairment had a 2.3 times greater risk of depression than those without a vision problem • Of visually impaired older people, 13.5% were depressed compared with 4.6% of people with good vision ('Depression and Anxiety in Visually Impaired Older People' Evans JR, Fletcher AE, Wormald RPL, Ophthalmology vol. 114, 283 - 288, 2007) • A survey of individuals registered blind and partially sighted in the past eight years reveals that only 8% of them were offered counselling in the eye clinic (Network 1000 Wave 2, 2008) • A survey of individuals registered blind and partially sighted in the past eight years reveals that only 15% of them were offered any form of emotional support in the year after registration (Network 1000 Wave 2, 2008)Excluding those who had been most recently registered (in the past 2.5 years) only 6% of surveyed blind and partially sighted individuals received emotional support in the preceding year • Research carried out by RNIB (Nelson, 1999) found that 83% of individuals surveyed who were attending eye clinics said that they had not been offered any emotional support from a professional resource One third of older individuals with poor vision or registered blind report a 'good' quality of life, compared with two-thirds of those with good or excellent vision ('An investigation of the circumstances of older people with sight loss: analysis of the English Longitudinal Study of Ageing. UCL research for Thomas Pocklington Trust, October 2006)
Cathy Yelf	Macular Society	Managing sight loss	Sight loss in elderly people can lead to depression, reduced social interaction, loss of	Sight loss will not be well managed if it is not identified. Undetected sight loss in care	

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			independence and falls.	homes: an evidence review. Jessica Watson and Sally-Marie Bamford, International Longevity Centre – UK, July 2012 identified the following key issues and barriers: • **Lack of awareness** of sight loss and visual impairment, associated health problems and symptoms at all levels, particularly residents, their families and care home staff and managers. • Similarly, across these groups there is a **lack of priority given to eye health**, commonly seen as an optional extra rather than an integral element of good health. This is particularly the case for residents who have dementia. There is not enough connection with good eye health as a contributing factor to a lower rate of falls, depression and isolation; and better quality of life. • **Eye health overlooked as a health indicator** in assessment and checks of care home residents; both internally as part of general health checks and externally through health professional consultations and CQC assessments. While eye health is referenced in general health outcomes, as a 'silent' health problem it is	

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				often missed off checks in practice. • Reflecting the lack of explicit inclusion of eye health indicators, there is a limit on the **time and organisational practices for informal sight checking** or assessing potential symptoms by case home staff, exacerbated by low awareness of the issue. • Training sessions and materials for care home staff on eye health and sight loss is available, but there are **limits in delivery of training** owing to restricted time, staff turnover and other practical barriers, such as shift working patterns.	
Cathy Yelf	Macular Society	Sight loss and dementia	These two conditions co-exist in many elderly people. Each can exacerbate the other. There is too little understanding of the impact of this co-morbidity.	Thomas Pocklington research paper, The experiences and needs of people with dementia and serious visual impairment: 2009, found that the two conditions together led to a profound sense of disorientation and sense of isolation • Sight loss professionals felt they were not equipped to work with people who had mental health needs, while dementia professionals felt the needs created by sight loss risked being overlooked in mental health services • Increased co-ordination	

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				between mental health and sensory impairment teams would help in identifying individuals' abilities and needs for support.	
Cathy Yelf	Macular Society	Awareness of visual hallucinations	Visual hallucinations are a common result of sight loss. When associated with visual impairment they are known as Charles Bonnet Syndrome. They are described as the 'normal' response of the brain to the loss of visual stimulation and are not a sign of mental illness. They may be mistaken for other conditions such as dementia.	A recent (as yet unpublished) survey of Macular Society members suggested that a large number of medical professionals are not aware of Charles Bonnet Syndrome. 38.4% of respondents to the survey said that the medical professional to whom they reported their hallucinations were 'unsure or did not know' what the hallucinations were. There are examples of people being referred to psychiatric services inappropriately and an he inappropriate response of care staff to residents reporting hallucinations.	Charles Bonnet Syndrome, Dr Dominic ffytche Digest, 2007. (Macular Society) Visual Hallucinations in Sight Loss and Dementia. Thomas Pocklington 2009. Visual Hallucinations and Charles Bonnet syndrome, Nursing and Residential Care June 2009 Vol 11, No 6
Peter Sims	RCGP	1.Urinary Continence	Dignity and self care	Incontinence is undignified and deeply distressing	Clinical experience, organising services
Peter Sims	RCGP	2.Appearance	Self pride and interest in appearance-clothes,hair,make-up	Pride in person, maintenance of sexuality	Depression is common in this group. It is never too late to buy a new hat!
Peter Sims	RCGP	3.Tailored care plan	The person, the staff and family agree a tailor made pattern of care with quality indicators	The person in Care needs to be as independent as possible for as long as possible. They can also care for each other and have control	Taking risks and getting wet in the rain are part of life and risk taking has to be Accepted and agreed
Peter Sims	RCGP	4.Teaching and learning	Learning is part of life and new skills can be achieved. Everyone	Everyone needs to have something to aim for and to	Use it or lose it…pride in achievement is a great prophylactic against depression and possibly dementia

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			has some skills	keep trying	
Philip King	CQC	**NICE Consultation – Mental wellbeing of older people in residential care: topic overview** Thank you for inviting comments at the first stage of the process for this topic. The over arching statement of intent is one we would like to endorse. We would however, like to point out that in designing a standard for this it is imperative to be aware of the fact that care homes are actually a persons home and not a clinical setting per se. Accordingly the notions of well being, purpose in life etc must be understood not in the context of a medical model construct of the world but in the social context of an individuals home. Account should be taken of the wider initiatives to deliver the relevant competencies for care staff as set out in the DH commissioned work from the sector			

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		skills councils. We would also urge you to consider how this topic development fits with the planned pilot of care home residents having a personal budget. The National Dementia Strategy does not seem to be included in the list of key policy documents and reports. There will need to be some clear communication and messaging about how this standard and others align with each other and are to be used alongside each other, without causing confusion for services. If this standard is being developed to steer clear from dementia and depression as there are other standards on such conditions, then is 'mental well being' the best title? If it is more broad than such specific conditions, might it be more helpful to have a broader subject title such as 'emotional well being' or 'quality			

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		of life'.			
Mr John Buchan, Mr Graham Kirkby and Mr Bernard Chang	The Royal College of Ophthalmologists	Uptake of Diabetic Retinopathy Screening by residential care home residents	Inequity in the uptake of Diabetic Retinopathy Screening (DRS) would be anticipated in the residential home population, just as it has been demonstrated in the population as a whole.	Early treatment of diabetic eye disease is protective against the need for more complex, often surgical, interventions necessitated by neglect of the early stages of disease. As DRS uptake is already monitored and included on the QOF then application of this same standard to the residential home population is already guaranteed in theory, but it may be that residential home residents are disproportionately represented in the non-attending group.	Diabetic retinopathy equity profile in a multi-ethnic, deprived population in Northern England. Eye. 2012 May;26(5):671-7. Kliner M, Fell G, Gibbons C, Dhothar M, Mookhtiar M, Cassels-Brown A
Mr John Buchan, Mr Graham Kirkby and Mr Bernard Chang	The Royal College of Ophthalmologists	Uptake of NHS-funded optometry eye tests	Visual impairment has been repeatedly demonstrated to have a negative impact on mental wellbeing. Regular NHS-funded sight tests are the main way that eye diseases, in particular cataract and glaucoma, are detected. Older people in residential care are already offered such an NHS optometrist eye test at least every two years, however, uptake of these tests is known to be variable, and lower levels of uptake in areas of relative socio-economic depravation has been demonstrated by Equity Profiling using late presentation as a marker.	If uptake of NHS funded optometry (GOS) sight tests yearly (if over 70) or past 2 years (if over 60) is not currently routinely monitored, however, it would be a good candidate to be added to the QOF nationally If this were achieved, it would drive quality improvement in care. Uptake of this eye testing permits early diagnosis and referral of both treatable conditions (eg cataract for operation), and untreatable conditions (such as some forms of Age-Related Macular Degeneration) for Certificate of Visual Impairment (CVI) registration which is a Public	Explaining the relationship between three eye diseases and depressive symptoms in older adults. Invest Ophthalmol Vis Sci. 2012 Apr 24;53(4):2308-13. Popescu M, Boisjoly H, et al. A glaucoma equity profile: correlating disease distribution with service provision and uptake in a population in Northern England, UK. Eye. 2010 Sep;24(9):1478-85 Day F, Buchan JC, Cassells-Brown A, et al.

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				Health Outcome Indicator and for Low Visual Aid (LVA) assessment. Without some impetus to improve uptake of GOS sight tests, in equity in eye health care and the ramifications for mental wellbeing of residential home occupants is inevitable. Mapping of residential homes and optometric services within a locality would show homes from which, residents who do not fulfil the eligibility criteria for NHS-funded domiciliary sight testing (i.e. they are not confined to their dwelling by physical or mental problems) might find difficulty in accessing community optometric services. Strategic deployment of community eye care services, such as optometry sessions in community centres or the establishment of Community Eye Centres linked to secondary care might overcome some of the barriers.	
Mr John Buchan, Mr Graham Kirkby and Mr Bernard Chang	The Royal College of Ophthalmologists	Promotion of eye testing in those diagnosed with dementia	Sensory impairment has a negative impact on cognitive function but it can be assumed that those with dementia are less likely to present early with reduced visual function.	People with dementia would frequently be eligible for domiciliary NHS-funded eye tests but without active encouragement they are less likely to avail themselves of this opportunity. As preserving or improving visual function is likely to	

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				have a positive impact on cognitive function and reduce dependency, it is important that uptake of the existing provision for eye tests is encouraged to minimise the impact of impaired sensory input in this population. At the point of diagnosis of dementia, patients who have not been seen by a community optometrist in the past year (if over 70) or past 2 years (if over 60) should be referred, or a domiciliary visit arranged if appropriate. Promotion of NHS funded optometry (GOS) sight tests should be every 1 to 3 years, dependent on whether their carers have concerns about sight impairment This “point of diagnosis” check for uptake of GOS testing would promote eye health which in turn would help maintain independent living for elderly dementia patients.	
Mr John Buchan, Mr Graham Kirkby and Mr Bernard Chang	The Royal College of Ophthalmologists	Referral for routine NHS sight testing prior to admission to residential home	Improving visual function would help permit some older people continue living independently longer.	Elderly people referred for a place in residential home who have not attended their NHS eye test in the past 12 months could be expected to do so, as improvement in vision might obviate the immediate need for the care offered in residential homes.	

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Barbara Monk-Steel	UK Council for Psychotherapy	Training in assessment and referral for residential care staff for psychological therapies for older people in residential care	The mental health of older people is a priority, and the need for training of residential care workers in the recognition of the mental health, emotional and psychological needs of the elderly and the knowledge of when to refer to qualified psychological therapists working with the elderly for expert assessment and intervention is significant for quality and equality within care	Physical health needs take precedence over mental health needs, and the referral to psychological therapist with appropriate skills for this client group is patchy. As the majority of residential facilities for the elderly are privately owned and run this may be an area of care that is neglected. There is advice available about integrated interventions to preserve mental health in residential care, but not about referral for specialist services accessible to those in residential care in the core reference documents.	Review of documents supporting the quality standards
Barbara Monk-Steel	UK Council for Psychotherapy	Provision of specialist services for psychological therapies for older people in residential care	The need for access to specialist services for the working adult is covered within NICE Guidelines and Quality Standards. There are significant differences in the needs of older adults in residential care	Under commissioning of services for this group were identified in the Ageism and Age Discrimination doc Centre for Policy on Ageing, and is missing form the focus of the other documents.	Review of documents supporting he quality standards
Cecilia Yardley	Parkinson's UK and Lewy Body Society	**Creating a 'Dignity in Care' culture in residential care**	Without a culture that recognises the rights of an individual to be treated with dignity, the kinds of abuses at Winterbourne View become tolerated and the mental and physical wellbeing of those being cared for (and those delivering care) is undermined.	Concerns about lack of 'dignity in care' are still raised frequently by people whose loved ones are in care homes and by staff involved in care sector workforce development.	***Dignity in Care*** campaign website and materials: http://www.dignityincare.org.uk/Dignity_in_Care_campaign/The_10_Point_Dignity_Challenge/ **PEACH: Promoting Excellence in All Care Homes** (2011) http://panicoa.org.uk/sites/assets/Tadd_PEACH_report.pdf **Relatives and Residents Association *Keys for Care***
Cecilia Yardley	Parkinson's UK and Lewy Body Society	**Ability of residential home staff to**	Parkinson's is the second most common neurodegenerative	People with Parkinson's are a significant minority group	Parkinson's UK are undertaking research into the experience of people with Parkinson's in residential care

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		respond to the needs of people with Parkinson's, especially: **Medication management** **Manual Handling** **Palliative Care** **Non motor symptoms:** **Communication** **Depression** **Apathy** **Sleep disturbance** **Swallowing**	condition in the UK, affecting around 1:1000 of the population. The prevalence increases with age, affecting around 1:200 of those over 75 years (Porter, Macfarlane et al. 2006). It is progressive and fluctuating with a range of motor and non-motor symptoms which can give rise to complex care requirements. The majority of patients will eventually develop mild cognitive impairment, and a significant proportion [50 per cent after eight years, 80 per cent after 20 years] will go on to develop dementia (Reid et al 2011, Aarsland et al 2001). Porter, Henry et al. (2010) found that 14 per cent of people with Parkinson's were living in residential or nursing homes, representing 1.6 per cent of the total nursing / residential home population). In the USA the prevalence of PD in nursing home residents ranges from five to seven per cent and patients with Parkinson's admitted to residential care have a 30% higher mortality rate as compared to community dwelling patients (Goetz and Stebbins 1995). Those in care have been seen to be significantly older with later stage disease, poorer cognitive function and poorer functional ability. See also: Walker,	within residential settings, with complex motor, mood and neuropsychiatric symptoms including falls, depression, hallucinations and dementia. Poor care for people with Parkinson's in residential homes can exacerbate problems and undermine mental wellbeing	**Get it on time: Medicine management for residents with Parkinson's DVD** http://www.parkinsons.org.uk/advice/publications/professionals/get_it_on_time_care_home_dvd.aspx Porter B, Macfarlane R, Unwin N, Walker R. The prevalence of Parkinson's disease in an area of North Tyneside in the North-East of England. Neuroepidemiology. 2006;26(3):156-61. Reid WG, Hely MA, Morris JG, Loy C, Halliday GM. Dementia in Parkinson's disease: a 20-year neuropsychological study (Sydney Multicentre Study). J Neurol Neurosurg Psychiatry. 2011 Sep;82(9):1033-7 Aarsland D, Larsen JP, Tandberg E, Laake K. Predictors of nursing home placement in Parkinson's disease: a population based prospective study. J Am Geriatr Soc. 2000 Aug;48(8):938-42 Aarsland D, Andersen K, Larsen JP, Lolk A, Nielsen H, Kragh-Sørensen P. Risk of dementia in Parkinson's disease: a community-based, prospective study. Neurology. 2001 Barnes L, Cheek J, Nation RL, Gilbert A, Paradiso L, Ballantyne A. Making sure the residents get their tablets: medication administration in care homes for older people. J Adv Nurs. 2006 Oct;56(2):190-9. Buchanan RJ, Wang S, Huang C, Simpson P, Manyam BV. Analyses of nursing home residents with Parkinson's disease using the minimum data set. Parkinsonism Relat Disord. 2002 Jun;8(5):369-80 Goetz CG, Stebbins GT. Mortality and Hallucinations in Nursing-Home Patients with Advanced

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			Sweeney, Gray 2011 and Aarsland, Larsen et al, 2000, Buchanan, Wang et al. 2002, Outcomes for PD patients admitted to residential care are worse than for those who are able to stay at home, with a lack of knowledge and understanding of the condition by care home staff resulting in sub-optimal care (Barnes, Cheek et al. 2006). The reasons for such deficiencies are likely to be multi-factorial. Services for patients with Parkinson's in institutional care can be more difficult to access, particularly for those with cognitive impairment and for those without a family member able to contact services on their behalf, and staff in institutional care may be less experienced in dealing with the condition and less familiar with the medications and their side effects. Patients with later stage Parkinson's may be severely disabled for long periods and require considerable help with activities of daily living. They may no longer be guaranteed a consistent response to their dopaminergic medication. Moreover, this can result in the prescription of a large number of anti-Parkinsonian drugs with significant time spent balancing the effects of drugs against side		Parkinsons-Disease. Neurology. 1995 Apr;45(4):669-71. Porter B, Henry SR, Gray WK, Walker RW. Care requirements of a prevalent population of people with idiopathic Parkinson's disease. Age Ageing. 2010;39:57-61. Richard Walker, William Sweeney, William Gray. Access to care services for rural dwellers with idiopathic Parkinson's disease. British Journal of Neuroscience Nursing 2011 7 (2) – (April/May) p494-496

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			effects.		
Cecilia Yardley	Parkinson's UK and Lewy Body Society	**Integration of specialist nursing and therapeutic support services, including Parkinson's specialist nursing and physiotherapy, into support available in residential care**	Several clinical trials have suggested that physiotherapy might substantially enhance both motor performance and quality of life (Keus, Munneke et al. 2009). Physiotherapists with PD expertise can provide specific interventions, such as cueing strategies to overcome freezing of gait. Care home residents with dementia and impaired mobility often have limited access to physical therapies, despite the potential benefits (Leemrijse, de Boer et al. 2007).	Caring for residents with complex needs may require the involvement of experts. Integrating these experts effectively into the residential home's team practices is important to ensure harmonisation of care and good transfer of skills and knowledge to improve resident wellbeing.	Keus SH, Munneke M, Nijkrake MJ, Kwakkel G, Bloem BR. Physical therapy in Parkinson's disease: evolution and future challenges. Mov Disord. 2009 Jan 15;24(1):1-14 LLeemrijse, C. J., M. E. de Boer, et al. (2007). "Factors associated with physiotherapy provision in a population of elderly nursing home residents; a cross sectional study." BMC Geriatr **7**:7 ***Persistent challenges to providing quality care: An RCN report on the views and experiences of frontline nursing staff in care homes in England*** (RCN, March 2012)
Cecilia Yardley	Parkinson's UK and Lewy Body Society	**Ability of residential home staff to respond to the needs of people with Lewy body dementias (Parkinson's dementia and dementia with Lewy bodies) in relation to:** Nutrition Hydration Stimulation (prevention/ alleviation of boredom Flexibility of schedules Medication	The symptoms of Lewy body dementias (Parkinson's dementia and dementia with Lewy bodies) pose complex challenges to physical and mental wellbeing, with core symptoms being: • Fluctuating attention • Visual hallucinations • Parkinsonism Dementia with Lewy bodies has been identified as a distinct condition since 1996 and is still poorly recognized [verbal reports at meetings from care home staff/managers and also from relatives through Lewy Body Society Facebook and conversations with carers].	Poor medicines management can seriously undermine the wellbeing of people with Lewy body dementias and, in the case of the use of antipsychotics, which may be prescribed because of the hallucinations, can be fatal. Understanding the nature of the condition, including daytime sleepiness and nighttime waking/night terrors can enable care home providers to put in place support that greatly enhances mental wellbeing.	**Living well with dementia in a care home: A National Dementia Strategy**(Department of Health Feb 2009) **www.lewybody.org/symptoms** **Lewy body dementia: the litmus test for neuroleptic sensitivity and extrapyramidal symptoms (**Baskys A. J Clin Psychiatry. 2004) http://www.ncbi.nlm.nih.gov/pubmed/15264967 **Caregiver burden in Lewy body dementias** http://www.lbda.org/node/474 **Low expectations: Attitudes on choice, care and community for people with dementia in care homes** (Alzheimer's Society, 2013) **Night Terrors and Parasomnias** http://www.patient.co.uk/doctor/Night-Terrors-and-Parasomnias.htm

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			Care home staff working with people with Lewy body dementias report that they are often some of the hardest residents to support [verbal reports at meetings].		
Cecilia Yardley	Parkinson's UK and Lewy Body Society	**Quality of design of living environment**	People with Parkinson's and/or a Lewy body dementia can be prone to visuo-spatial problems, hallucinations and falls. Appropriate design of the living environment can prevent these problems that contribute to poor mental health Areas for consideration include: • lighting • colour schemes • floor coverings • assistive technology • signage • wide doorways • flat gardens, low-wall flower beds • glass-fronted cupboard doors in kitchens so people can see what is inside • memory cues • colour contrasts • minimising reflections and glare de-cluttering notice boards and living spaces	Design of living environments that support people with visuo-spatial problems is not intuitive – expert knowledge about the impact of colour, pattern and other design elements is required.	**Developing supportive design for people with dementia** http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia
Cecilia Yardley	Parkinson's UK and Lewy Body Society	**Access to nature/'green exercise'**	Care home residents have shown improved wellbeing when enabled to experience the natural world	Access to nature is often overlooked for people with dementia and/or complex physical challenges	Living with dementia and connecting with nature (Dementia Adventure, 2011) http://www.dementiaadventure.co.uk/uploads/green-exercise-and-dementia-neil-mapes-february-2011.pdf

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					Ecotherapy: the green agenda for mental health (MIND, 2007) http://www.mind.org.uk/assets/0000/2138/ecotherapy_report.pdf
Dr Gill Turner	British Geriatrics Society	Key area for quality improvement 1 **Availability of Specialist Medical and Nursing Care for Older people in Care Homes**	Mental Well Being will include; • Education and support to Staff in Care homes in the identification of mental illness, • support for the treatment of mental illness including medication and non medication treatments. Support for the management of frailty syndromes which contribute to feelings of well being	Evidence from various sources summarised in next column 1. Limited access for care home residents to specialist geriatric care. Only 60% of PCTs have ensured access to a geriatrician. 11% of PCT's have ensured no access to psychiatry for residents in care homes. 2. Variable access of care home residents to community health services. CQC's data shows significant variations in the specialist services available to older people (including mental health teams, dietetics, occupational therapy, physiotherapy, podiatry, continence, falls and tissue viability) with 52 different combinations across 152 PCTs. Only in 43% of PCTs are older people likely to have access to all the services listed above. 3. Healthcare commissioners interest in their services for care homes is limited. PCTs can use response or waiting time	The BGS has produced 2 reports – Quest for Quality (2011) Report of a joint working party into the quality of health care support for older people in care homes http://www.bgs.org.uk/campaigns/carehomes/quest_quality.doc AND Failing the Frail (2012) a review of the CQC's own data(published under a data share agreement) which supported the BGS findings of the previous year. The summary of this report is in the previous column. http://www.bgs.org.uk/pdf_cms/reference/Failing_the_frail_full_report.doc

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				standards to ensure that people can access their services. PCTs had set a standard and provided data for just 39% of care home specific services. 40% of all services lacked a response standard. While 87 (63%) PCTs monitored all the response standards they had set, 50 (36%) only monitored some. Furthermore, response standards varied greatly between services and areas. Some providers had testing response standards of two weeks or less, but standards of between six to eight weeks were common and the general NHS '18 week target' was used for 31% of services. Despite these non-ambitious standards, they were not met in nearly half of services for which there was data.	
Professor Bob Woods	British Association for Behavioural & Cognitive Psychotherapy	Key area for quality improvement 1 **Access to individual psychological therapy for common mental health disorders**	Levels of anxiety and depression are high in residential care homes, and yet access to evidence-based psychological therapies is poor for older people in general and especially so for those in care homes.	Anxiety and depression lead to significantly reduced mental well-being and excess disability. Levels are high on and before admission to a care home, and are not simply a reaction to the care home environment (although this serves to maintain low mood in many cases). Although frequently co-morbid with dementia and mild cognitive impairment,	Age Concern Inquiry into mental well-being in later life – second report Woods, R. & Roth, A. (2005). Effectiveness of psychological interventions with older people. In: Roth, A. & Fonagy, P. (eds) *What works for whom? A critical review of psychotherapy research.*(second edition) (pp. 425-446). New York: Guilford. Woods, B., Clare, L., & Windle, G. (2012) Dementia and related cognitive disorders. In: Sturmey, P. & Hersen, M. (eds) Handbook of evidence-based practice in clinical psychology.

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				cognitive behaviour therapy has now been shown to be feasible in this context.	
Professor Bob Woods	British Association for Behavioural & Cognitive Psychotherapy	Key area for quality improvement 2 **Evidence-based interventions that lead to improved quality of life for people with mild to moderate dementia**	Group interventions such as Cognitive Stimulation Therapy have been shown to be effective in improving quality of life in people with mild to moderate dementia, and cognitive stimulation is recommended by the NICE-SCIE dementia guideline.	Although clearly applicable in the residential care home setting (where many of the research studies have taken place), the implementation of cognitive stimulation and similar approaches (e.g. individual life review / life story book work) is patchy.	Cochrane review on Cognitive Stimulation. Woods, B., Aguirre, E., Spector, A., Orrell, M. (2012) Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews* 2012, Issue 2. Art. No.: CD005562. DOI: 10.1002/14651858.CD005562.pub2. Subramaniam, P., & Woods, B. (2012). The impact of individual reminiscence therapy for people with dementia: systematic review. *Expert Reviews in Neurotherapeutics,* 12 (5), 545-555.
Professor Bob Woods	British Association for Behavioural & Cognitive Psychotherapy	Key area for quality improvement 3 **Staff training and support in person-centred care approaches for people with dementia**	What marks out residential care from care in the person's own home is the key role of staff and others in shaping the care environment and the care experience for residents with dementia. There is no doubt that person-centred approaches are associated with positive outcomes, but although there is much talk of person-centred care, there remains much to be done in terms of training, development and leadership.	Quality of life and quality of care come close in dementia care and there is a clear need to raise the standards of care provided, so that it is individualised, valuing of the individual and reflecting an understanding of the person in the context of their biography, personality, preferences and needs.	Chenoweth L et al (2009) Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology,* Volume 8, Issue 4, 317 – 325. Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. and Howard, R. (2006), ''Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial'', British Medical Journal, Vol. 332, pp. 756-8.
Professor Bob Woods	British Association for Behavioural & Cognitive Psychotherapy	Key area for quality improvement 4 **Staff training in approaches that reduce behaviour that challenges for people with dementia**	Behavioural and functional analysis are recommended as key components of the assessment process by the NICE-SCIE guideline, and yet there is little evidence of the widespread use of these approaches.	Behaviour that challenges may be an indication of distress from a person with dementia, and may be stressful for other residents and staff. It is associated with reduced well-being.	Bird, M. & Moniz-Cook, E. (2008). Challenging behaviour in dementia: A psychosocial approach to intervention. In R. T. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing* (2nd ed.) (pp. 571–594). Chichester, England: Wiley.
Professor Bob Woods	British Association for Behavioural & Cognitive	Key area for quality improvement 5 For people with	For people with dementia, maintaining relationships with family members after admission	Evidence suggests that quality of life is greater for people with dementia when	Gaugler, J.E., Anderson, K., Zarit, S.H. and Pearlin, L.I. (2004), ''Family involvement in nursing homes: effects on stress and well-being'', Aging & Mental Health,

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	Psychotherapy	dementia, maintain Involvement of families in care home	to a care home is challenging, and family members may find it difficult to visit or know how best to be involved.	family members continue to stay involved. The relationship between family and the care home is a clear quality marker.	Vol. 8, pp. 65-75. Woods, B., Keady, J., Seddon, D. (2007). *Involving families in care homes: a relationship-centred approach to dementia care.* London: Jessica Kingsley.
Catharine Ward Thompson	University of Edinburgh	Key area for quality improvement 1 Attractive and well-designed gardens available for easy, independent access outdoors.	Access to outdoor and natural environments is often not provided such that it is attractive and readily accessible and usable. The issues are both to do with design of outdoor spaces that are easy, convenient and pleasant to use, and with care-home systems of management and staff. Access to gardens may often be kept locked or blocked in practice, making it hard for people to use gardens when they feel like it. Carers should be expected to assist and encourage outdoor use on a daily basis whenever possible.	Access to outdoor and natural environments is associated with better quality of life for older people. It is associated with people remaining more active but also assists with maintaining good circadian rhythms of wakefulness and sleep, aids Vitamin D production and combats seasonal affective disorder	http://www.idgo.ac.uk/older_people_outdoors/use_of_outdoor_environments.htm Gillie, O. Sunlight, Vitamin D and Health. Health Research Forum occasional reports no. 2, London, 2005 www.healthresearchforum.org.uk Zeisel, J. Healing gardens for people living with Alzheimer's: challenges to creating an evidence base for treatment outcomes. In Ward Thompson, C. and Travlou, P. (eds) 2007 *Open Space: People Space*. Abingdon, UK: Taylor and Francis. Sugiyama, T., Ward Thompson, C. and Alves, S. 2009. Associations between neighborhood open space attributes and quality of life for older people in Britain. *Environment and Behavior*, *41*(1), 3-21 Ward Thompson, C. 2010 'Landscape quality and quality of life', in Ward Thompson, C., Aspinall, P. and Bell, S. (eds) *Innovative Approaches to Researching Landscape and Health: Open Space: People Space 2*, Abingdon: Routledge, 230-255 Schmoll C, Lascaratos G, Dhillon B, Skene D, Riha RL. The role of retinal regulation of sleep in health and disease. Sleep Med Rev 2011;15(2):107-13
Dr Mo Ray	NICE fellow	Regular and apropriate opportunities for participating in	Meaningful occupation can support identity maintenance; encourage a person to continue to use their skills and abilities (or	Current evidence suggests that meaningful occupation in care homes is variable and that under	e.g. Skingley, A. Bungay, H. 2010 The Silver Song Club: Singing to promote the health of older people, Briitsh Journal of Community Nursing 15 (3) 135 – 140 (qualitative study)

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		meaningful occupation and activity	develop new ones); encourage participation and social engagement. All of these factors are important for mental health and well being – and may also offer a useful non-pharmacological treatment for people with signs of depression	occupation/occupational deprivation is a significant concern.	Clift, S. Coulton, S. Rodriguez, J. (2011) The effectiveness and cost effectiveness of a participative community singing programe as a health promotion initiative for older people (protocol for RCT) Shorter. V (2011) Creating a hospital based arts project for older people, Mental Health Practice, 15(3) 24-26 McDaid, D. and Park, A.L. (2011) Investing in Mental Health and Wellbeing: Findings from the dataprev project, Health Promotion International, 26 108 – 139 Forsman, A. Schlerenbeck, I. Wahlbeck, K. (2011) Psychosocial interventions for prevention of depression in older adults: systematic review and meta analysis Jounral of Aging and Health 23 (3) 387-416 Routasolo, P. Reijo, T. Hannu, K. Kalsu, P. (2009) Effcts of Psychosocial Group Rehabilitation on social functioning, loneliness and wellbeing in lonely older people, Journal of Advanced Nursing 65 (2) 297-305 Mental Health Foundation (2011) An Evidence Review of the Impact of Participatory Arts on Older People, London, Mental Health Foundation Hallam, S. (2012) Music for Life Project: The Role of participation in community music activities In promoting social engagement, New Dynamics of Ageing, University of Sheffield National Institute for Clinical Evidence (2008) *Mental Wellbeing and Older People, Public Health Guidance 16,* *http://www.nice.org.uk/nicemedia/pdf/PH16QuickRefGuide.pdf* See also: Alzheimer's Society – Singing for the Brain.
Dr Mo Ray	NICE fellow	Addressing sensory impairment and making reasonable adjustments to accommodate sensory impairment.	Evidence of the prevalence of hearing/visual/dual impairment in care home environments. Evidence of under recognition of sensory impairment and failure to promote use of supportive aids and technology.	Impact on mental health is well known. Impact on ability of older person to participate in other aspects of their life and life of the care home / community	See for example, Action on Hearing Loss A World or Silence 2012 Reports from the Thomas Pocklington Trust
Dr Mo Ray	NICE fellow	Individualised care	Challenging the potential for	The importance of thinking	See University of York – systematic reviews on the use of

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		using life history and biography to support individual person centred planning	individuality and identity to be overlooked in the context of collective care.	about individual preferences and aspirations; focusing interventions based on individual preference and interest	reminiscence and life history in dementia and in older populations
Dr Mo Ray	NICE fellow	Improvement of social networks / tackling loneliness	Older people in collective care settings may be isolated and lonely. They may have been separated from long standing social and support networks – a reason for admission may relate to the loss of a spouse/partner/close relative.	Mental health promotion	See above e.g. Routasoulo et cl. Highlighted the benefit of forming new friendships and developing social networks. Cattan, M. (2005) Preventing Social Isolation and Loneliness: A systematic Review of health promotion interventions, Ageing and Society, 25 (1) 41- 67 Victor, C. Prevalence and risk factors for loneliness, Ageing and Society, 25 (3) 2005
Dr Mo Ray	NICE fellow	Physical activity	Links between physical activity and mental health and well being; importance of keeping physicall active in later life	Under activity of people living in care homes; patchy practice regarding physical activity and exercise Falls prevention Avoiding skills disuse atrophy Promoting and sustaining mastery, confidence and self esteem	World Health Organisation (2010) *Global Recommendations on Physical Activity for Health,* Geneva, World Health Organisation Department of Health (2011) *UK Physical Activity Guidelines,* London, Department of Health Foster C, Hillsdon M, Thorogood M, Kaur A, Wedatilake T. Interventions for promoting physical activity. Cochrane Database of Systematic Reviews 2005, Issue 1. Art. No.: CD003180. DOI: 10.1002/14651858.CD003180.pub2 Liu C-j, Latham NK. Progressive resistance strength training for improving physical function in older adults. Cochrane Database of Systematic Reviews 2009, Issue 3. Art. No.: CD002759. DOI: 10.1002/14651858.CD002759.pub2 Alzheimer's Society (2011) *Keeping Active and Staying Involved, Fact Sheet,* London, Alzheimer's Society http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=90

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					Blundell, A. Gordon, A. and Masud, T. (2010) *Physical Activity in older age: British Geriatrics Society Best Practice Guide* Royal College of Physicians (2012) *Older Persons' experiences of therapeutic exercise as part of a falls prevention service,* London, Royal College of Physicians www.rcplondon.ac.uk COLEMAN, R. J., KOKOLAKAKIS, T. & RAMCHANDANI, G. (2011) *Walking for Health Attendance Study.* Natural England Commissioned Reports, Number 098. Lee. L. K. Lee D.T and Woo. J (2010) Psychosocial effects of Tai Chi on nursing home residents. Journal of Clinical Nursing. 19 7/8 927-938