

# Exploring dementia and agitation

How public policy needs  
to respond



Health and care  
Carers  
Community  
Life expectancy  
Care homes  
Culture and society  
Connections  
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## Summary

With 850,000 people living with dementia in the UK, there is a significant need to understand how to improve quality of life for them and their carers. This report summarises the findings from the MARQUE study, the largest ever study of people living in care homes, which looked at critical issues among those living with dementia and their paid and unpaid carers.

### **Key findings from the research include:**

- Agitation is common in people with dementia. It reduces quality of life and is difficult to improve. Some exceptional families are able to cope with people at home, but more action is needed to help other families adopt the same strategies to cope better.
- When people with dementia and agitation are admitted to care homes, staff are often not able to deliver the quality of care that people would want for their relatives or what the staff members themselves may wish to deliver. Staff are also not regarded as people whose own personhood is important.
- Care homes are complex systems, and having something available like activity groups does not mean people with agitation are enabled to use them. Even an intervention that can improve quality of life may not be enough to reduce agitation. Resources to implement interventions, rather than expect staff to change within a complex system, are necessary.

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## About dementia and agitation

Worldwide, the number of people living with dementia is estimated to be 47.5 million and is projected to increase to 75.6 million by 2030.<sup>A</sup> In the UK, there are 850,000 people living with dementia.<sup>B</sup> Around 70% of older people with dementia live at home and are supported in the main by their families.<sup>C</sup> There are 300,000 people in the UK living in care homes, and about 70% of these residents have dementia, often with high levels of neuropsychiatric symptoms, such as agitation and sleep disturbance.<sup>B,D</sup>

People with dementia can exhibit agitation: a range of behaviours including restlessness, pacing, repetitive vocalisations, and verbally or physically aggressive behaviour. Agitation accounts for about 12% of overall health and social care costs for people with dementia and is the most common neuropsychiatric symptom.<sup>E</sup> About 10% of people with mild cognitive impairment display agitation, 15% of people with dementia presenting to memory clinics do so, and 30% of those living in the community do so.<sup>E</sup>

In care homes, agitation is associated with lower quality of life and higher care costs and is persistent and distressing.<sup>D</sup> It is thought that agitation arises from unmet needs, rather than solely from worsening brain function.<sup>D,E</sup> There is also a lack of evidence that interventions and/or more social interactions can help to improve agitation or quality of life in care home residents.<sup>E</sup>

Agitation has not been a strong focus of dementia policy. In 2014 the National Institute for Health Research (NIHR) and the Economic and Social Research Council (ESRC) provided funding for MARQUE as a first step in understanding the impact of agitation on people living with dementia and their paid and unpaid carers.

Managing Agitation and Raising Quality of Life in Dementia (MARQUE) is the largest ever study involving people living in care homes. MARQUE was divided into six workstreams:

- Stream 1: Conceptual research of personhood in dementia
- Stream 2: A two-year cohort study of agitation and quality of life in care homes
- Stream 3: A cluster randomised controlled trial to help train care home staff and improve agitation for people with dementia in care homes
- Stream 4: A qualitative study of people with moderate to severe dementia and their family carers in domestic environments
- Stream 5: Agitation in people with severe dementia in care homes and hospitals: an ethnographic approach
- Stream 6: Piloting an intervention to improve quality of life of people with dementia in the last 6 months of life

This paper summarises findings from MARQUE and discusses their implications.

## Prevalence of agitation and effect on quality of life

The MARQUE study, which is the largest ever study of care home residents with dementia (1,483 individuals), found that 86% of all residents had dementia and, of those, 40% had clinically significant agitation symptoms and 86% had some symptoms of agitation.<sup>E</sup> Prevalence of agitation in care homes was not affected by the care home environment, staffing levels, or availability of activities.

It is clear that agitation affects the quality of life of people living with dementia. Staff and family carers judged quality of life as lower in people with dementia who displayed agitated behaviours, and the more symptoms of agitation they had, the lower quality of life ratings were.<sup>E</sup> Staff and family members rated quality of life differently; staff members judged quality of life to be more related to current quality of care, while family ratings were more related to the losses their relative had experienced with dementia.<sup>H</sup> Overall family judged quality of life as less than staff.<sup>A</sup>

Another MARQUE study found that staff using more dysfunctional coping strategies did not mean that residents living with dementia had lower quality of life or greater levels of agitation. Residents' level of agitation also did not reduce over time.<sup>F</sup> This suggests that what causes agitation is complex. For example, MARQUE found that people in care homes who speak English as a second language experience more agitation.<sup>G</sup> As people develop dementia, they often lose their second languages, and this suggests that residents who were unable to communicate in English became frustrated and agitated. When staff members shared the same language, they found it easier to manage the agitation.<sup>G</sup>

## Measuring quality of life

Quality of Life (QoL) is an important outcome for people living with dementia in care homes but usually needs to be rated by proxy, as people with dementia are not able to complete the measures themselves. Research has consistently found that self-reported QoL is rated higher than proxy-reported QoL.<sup>A</sup>

MARQUE researchers conducted a review of data investigating whether and how these proxy reports of QoL differ between family and care worker responses for people with dementia in care homes.<sup>A</sup> In care homes, people are more likely to have severe dementia and less likely to be able to self-report, so proxy-reported QoL is necessary. Relative and staff proxy QoL ratings share a clear relationship with residents' physical and mental health including: lower weight, use of antipsychotic medication, depression, higher physical disability, pain, poorer cognitive function, and lower capacity to carry out activities of daily living.

Another MARQUE study investigated whether there were differences between proxy ratings of QoL (using a dementia specific QoL measure called DEMQOL) by care home staff versus proxy ratings by family members.<sup>H</sup> The study did not find clinically meaningful differences between staff and family member ratings. However, staff tended to focus on the quality of care when determining ratings, whereas family members compared the person's quality of life to what they might have had before. The study concluded that staff and family member proxy ratings should not be used interchangeably.

## Cost of dementia and agitation for people living in care homes

Using baseline data collected through MARQUE, researchers measured for the first time the costs for care home residents with different levels of dementia. Costs for the last four months were recorded for health and social care usage (including, for example, GP, practice nurse, accident and emergency attendance, use of community services, prescriptions).<sup>1</sup> Agitation was measured using a measure called the Cohen-Mansfield Agitation Inventory (CMAI). Costs increased as the CMAI score increased. This suggests that measures or interventions to reduce agitation, as well as improve quality of life, might prove value for money by reducing the use of healthcare resources, over and above any effect on preventing entry to care homes.

**Table 1: Annual mean costs per resident by CMAI score<sup>1</sup>**

	<b>CMAI ≤ 45</b>	<b>CMAI &gt; 45</b>
<b>Overnight inpatient stay</b>	£10,761.23	£11,054.83
<b>Outpatient contacts</b>	£431.04	£398.33
<b>Accident and Emergency contacts</b>	£439.46	£467.08
<b>Primary care, community health, or emergency contacts</b>	£765.88	£802.76
<b>Social care contacts</b>	£166.43	£431.43
<b>Community-based service contacts</b>	£420.24	£431.43
<b>Other medical-based professional contacts</b>	£1,110.43	£1,092.87
<b>Prescriptions</b>	£312.81	£360.82
<b>Total cost</b>	£2,410.21	£2,800.66

<sup>1</sup>Note that CMAI > 45 is the level at which most professionals would consider providing treatment.



Adjusting the costs by CMAI score, the adjusted annual expected cost of residents with no clinically significant agitation was £1,439.04 and for those with agitation it was £2,564.39. This means that there is an excess annual cost due to agitation of £1,125.34 – 44% of the health and social care costs of dementia in care homes.

## Impact of managing agitation on care home staff

MARQUE explored how care home staff support people living with dementia who have agitation and how staff themselves cope with caring for residents. Staff quality of life ratings of residents are affected by their own levels of stress and burnout.<sup>A</sup>

Findings from a MARQUE qualitative study showed that staff in care homes recognise that agitation is caused by a variety of factors and try to take a person-centred approach to identify the underlying causes of a person's agitation. However, staff sometimes struggle to deliver this because of their own emotional response, e.g. not knowing how far to play along with a person's disorientation, or financial and managerial factors. There is a tension between task-focused and person-focused approaches, for example, completing a task by a certain time versus leaving washing or dressing until the resident is ready for it. Financial constraints affect care, with staff in all care homes describing a business culture that conflicts with a person-centred care approach, limiting staffing levels and time. Staff said they did not feel supported by management or have sufficient training. A negative perception of care homes in the media also led to the lowering of staff morale.<sup>D</sup>

Staff also found maintaining a person-centred approach harder when people with dementia exhibited difficult behaviours, e.g. swearing at them. The most common behaviour that staff found hard was verbal and physical aggression when staff provided intimate care. Staff saw physical needs as more valid to attend to, so emotional needs (e.g. reassurance) were lower on the priority list. Staff's emotional responses included feeling powerless or disheartened, frightened but trying not to react. Staff also commented that the environment provides a lack of stimulation. Sustainable and practical interventions which support staff therefore need to be developed.<sup>D</sup>

In another MARQUE study, based on a qualitative analysis of 25 interviews of care home staff, researchers found that care staff were not always accepted as dignified persons in their own right, and organisational pressures and lack of control over

their work affects how care home staff value themselves. In order to provide person-centred care to people with dementia, care home staff sometimes are denied dignity and respect, e.g. by accepting abuse. Care home staff can find it difficult to balance organisational and procedural pressures and their wish to genuinely provide person-centred care. They feel that management do not always provide sufficient support or recognise staff needs as a problem when there are residents to consider. The researchers concluded that:

*Caring is complex and challenging work, in which the skilled and moral work of carers is often unacknowledged and where carers have their own needs and vulnerabilities subjugated to caring for those with dementia.<sup>1</sup>*

## Person-centred behaviours in care homes

A MARQUE survey of 1,544 staff in 92 English care homes found reports of both negative and positive staff behaviours.<sup>K</sup> A majority of staff reported that most of the time staff spoke nicely to residents (89%), often enjoyed spending time keeping them company (57%) and spent time getting to know them (63%). Person-centred activities were infrequent however:

- 34% of care home staff said they were never aware of a resident being taken out of the home for their enjoyment.
- 15% said they were never aware of residents engaging in an activity planned around a resident's interests.

More concerningly, a majority of staff (51%) reported witnessing or carrying out potentially abusive or neglectful behaviours "at least sometimes" in the last three months. Some abuse was reported "at least sometimes" in the last three months in all but one of 92 care homes. Of these abusive behaviours, neglect was most frequently reported (e.g. residents not having enough time to eat, avoiding residents with challenging behaviour). However, 1.1% of staff reported that residents had been hit or shaken and 4% of staff were aware of physical violence to residents.

There is a greater likelihood of staff reporting potentially abusive behaviour when staff are working in a care home with higher staff burnout scores.<sup>K</sup> Burnout is when staff experience physical, mental, or emotional exhaustion that might also accompany a change in attitude from positive and concerned to negative or unconcerned; this can be measured via a survey. Researchers noted that abuse should not be viewed solely because of the actions of single individual care home staff and can only be reduced by recognising that measures need to be put in place systematically within a care home.

The concept of person-centred care is understood by care home managers, but its full implementation is lacking, so, for example, people are rarely taken out of care homes.<sup>K</sup> This may be because of fears of falling or insufficient staff numbers, or it could be related to whether leaving the care home is desired

by the people living with dementia. Another paper, which explored the complex concept of how to acknowledge the personhood of the person living with dementia, concluded that taking appropriate and personal care of people living with dementia perhaps matters more than maintaining a focus on personhood.<sup>4</sup>

## Agitation in the home

MARQUE conducted the first qualitative study of family carers' approaches to caring for relatives with agitation.<sup>c</sup> These were unusual family members in that they were all managing to care at home, whereas agitation often leads to a breakdown of home care. Like care home staff, family carers find responding to agitated behaviours difficult and hard to cope with; however, once family carers recognised that their relatives had agitation as a result of their dementia, these family members developed and used a variety of strategies to manage the agitation. These strategies included problem solving and managing their own emotions. The table below lists the range of strategies that family carers used to manage agitation.

**Table 2: Approaches to managing agitation in the home by family carers**

Problem solving		Emotion-focused	
<b>Strategies to prevent agitation</b>	<ul style="list-style-type: none"> <li>Working out and responding to the cause of agitated behaviour</li> <li>Keeping a routine</li> </ul>	<b>Looking after themselves</b>	<ul style="list-style-type: none"> <li>Emotional support</li> <li>Time for themselves</li> <li>Practical support</li> <li>Paid support</li> </ul>
<b>Reducing agitation</b>	<ul style="list-style-type: none"> <li>Communication</li> <li>Providing comfort and reassurance</li> <li>Activities and interests</li> </ul>	<b>Accepting the problem</b>	<ul style="list-style-type: none"> <li>Understanding agitation as part of dementia</li> <li>Allowing the behaviour to continue</li> <li>Walking away</li> </ul>

<p><b>Preventing agitation from escalating</b></p>	<ul style="list-style-type: none"> <li>• Being calm, respectful and avoiding arguments</li> <li>• Keeping people safe</li> <li>• Allowing behaviour to continue</li> <li>• Walking away</li> </ul>		
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Family carers need better support to manage agitation. Awareness of behaviours that are due to agitation and part of an illness among family carers is the first step to lead them to feel better supported. The strategies listed above – e.g. to look after themselves, ask for help, communicate, and keep life predictable – may also help. There should be randomised controlled trials of interventions.

## Psychosocial interventions and outcomes for people living with dementia in care homes

Interventions may help people living with dementia in care homes to have a better quality of life and may help with the symptoms of dementia, including agitation. MARQUE conducted a systematic review of qualitative and quantitative intervention studies. There is mixed evidence about the effectiveness of psychosocial interventions. When trial interventions finish, results of the interventions are not sustained; when trial interventions are replicated, results are rarely the same.

Researchers reviewed which factors support interventions and which do not, in terms of individual factors, social and team factors, and organisational factors. Interventions should:

- be interactive;
- improve communication;
- encourage staff to reflect on practice.

Barriers to interventions include:

- staff doubts about ability to implement interventions, either learning new skills (e.g. singing) or engaging with relatives;
- staff concerns about how providing more personal care might impact their own feelings;
- staff concerns about additional workload;
- lack of cooperation and/or ownership between teams;
- lack of time;
- high staff turnover;
- low staff ratios;
- other changes occurring at the same time, e.g. new IT systems.

It is easier to implement interventions when:

- staff are informed of the benefits for staff and residents and observe, e.g. reduced agitation;



- all staff are involved in training;
- there is on site support;
- management are supportive;
- interventions are built in to routine care.

The study explored what needs to happen to ensure sustainability of interventions to continue when trials have finished. Helping staff to practise skills and reflect between sessions may motivate them to continue to use such skills, and staff should retain materials developed for the intervention.

MARQUE also conducted a randomised controlled trial of an intervention across 20 care homes. The intervention comprised six sessions of staff training but was not found to reduce agitation. It was cost-effective in that quality of life was increased at little cost. Other intensive interventions – including elements of staff training, increased social interaction, clinician reviews of medical history and medication, twice-weekly activity sessions, and more – have produced clinically significant reductions in agitation. Part of the purpose of this trial was to test whether less intensive interventions, such as the one tested, would be effective at reducing agitation, but this was not the case for the intervention trialled.<sup>M</sup>

## Implications of MARQUE

MARQUE provides evidence that agitation is a significant issue for people living with dementia, care home staff, and families. The focus of dementia policy has been on improving diagnosis and providing early intervention; MARQUE makes the case that more needs to be done to develop interventions and support families and staff in order to reduce agitation in people living with dementia. Not only will this help improve the quality of life of those with dementia and paid and family carers, but it will also potentially reduce the cost of care. The Department of Health and Social Care (DHSC) needs to ensure it addresses the issue of agitation in future policy initiatives. In particular, family carers need better awareness of agitation and the behaviours it comprises so that they feel better able to cope.

People with dementia who speak English as a second language experience more agitation than people who have English as a first language. The number of people from Black and Minority Ethnic groups with dementia in England is expected to increase seven-fold in the next 40 years, so this issue will become more pressing and consideration needs to be given to appropriate solutions, perhaps by the DHSC and Skills for Care considering how this could shape the skills of the social care workforce.<sup>9</sup>

However, investing in current strategies, such as increasing staff to resident ratios, putting on activities within the care home, and improving the environment, are not likely in themselves to be enough to reduce agitation, possibly because residents who are agitated may be excluded from activities or avoided by staff. Future research should explore personalised approaches to agitation and tools to help staff understand, communicate, and engage with people living with dementia.<sup>5</sup> New interventions, taking into account MARQUE findings about what works, need to be designed and trialled to identify cost-effective ones that help reduce agitation and improve quality of life. NIHR should continue to fund research into agitation and interventions to mitigate it.

It is clear from MARQUE that management and staff, though

they understand the importance of person-centred care, can struggle to deliver it meaningfully to people living with dementia. In addition, staff can experience burnout as a result of their caring duties. Most concerningly, there are widespread instances of abuse and neglect in the majority of care homes. There are about 15,000 care homes in England, which may be local authority, privately, or voluntary sector owned, and they are regulated by the Care Quality Commission (CQC). Care home staff often have little training and are low paid, with high staff turnover.<sup>K</sup>

Though there are standards to which care homes are held to account when inspected by CQC, a CQC review of 129 care homes providing dementia care in 2014 found that 29% did not carry out adequate assessments of residents, and in 34% there were aspects of poor care in meeting people's mental health, emotional, and social needs.<sup>2</sup> Consideration needs to be given to adequate regulation of care homes to ensure abuse does not occur, as well as how to support care home staff better so they are able to provide care to the highest standards. The Care Quality Commission and other regulators need to ensure sufficient support of staff are explicitly included in quality standards, and care homes also need to make sure that staff are better supported by employer policy and practice.

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<sup>2</sup><https://www.cqc.org.uk/news/stories/review-dementia-care-services-shows-too-much-variation>

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