

THE RELATIVES & RESIDENTS ASSOCIATION



Submission of evidence

to the All Party Parliamentary Group on Dementia Inquiry into the dementia care skills of social care staff supporting people with dementia in care homes and their own homes

1. The Relatives & Residents Association

The Relatives & Residents Association (R&RA) exists to promote the rights and wellbeing of older people living in care homes by providing advice and support to them and their relatives, especially at times of crisis.

It is the only national charity concentrating wholly on the specific and detailed needs of older people who are living in residential care because of frailty, ill-health, dependency and, increasingly, due to dementia. The R&RA deals with around 3000 calls to its advice line each year on matters related to older people living in care homes.

2. The R&RA submission

Following our earlier submission to the All Party Parliamentary Group on Dementia (APPG)D in which we expressed our concern about the inappropriate and excessive use of medication in care homes, we are now pleased to submit our comments in relation to workforce issues.

Our concerns cover a number of issues:

2.1 Communication

One of our chief concerns is the difficulty that people with dementia have in communicating with those around them. It is difficult for them even when they are surrounded by those who know and love them and have done so for many years. Living in a care home, the person with dementia is inevitably removed from the everyday familiarity of place and loved ones. It is essential that care homes do their utmost to compensate for this, both by providing safe, nurturing, well-designed environments that can easily become familiar and by employing staff who have the ability to develop the communication skills that are essential for building relationships with the people they care for and their relatives and friends, so that they may participate appropriately in the care of the resident.

Our concern is that too often communication in care homes is poor. Many residents with dementia are struggling with cognitive impairment, often undiagnosed or ineffectively treated. It is imperative that communication with people with dementia is clear.

Many care staff do not have English as their first language. People with dementia find it difficult to understand what is being said to them and in return find it hard to be understood by those caring for them. Communication abilities ought to be considered during staff recruitment processes. Time needs to be allowed for care staff to spend time with residents to build their mutual familiarity and develop techniques of communicating with each other. Our experience, which is also confirmed by research, reveals how little time during 24 hours staff spend on informal time (as opposed to task-centred time) with their residents.

2.2 Life experience

Many staff in care homes are young with very limited experience in their own lives of some of the difficult situations that dementia creates for those living with it and those who care for them. Callers to our advice line often say that care staff in their relatives' care homes are just too young to understand the problems they are dealing with. A study of CSCI inspectors' reports of inspection visits to care homes just completed by R&RA, found they too noted similar remarks from relatives. While age alone should not be a defining criterion for recruitment, care home managers need to reflect on the importance of creating a balanced workforce so that the care needs of residents can be properly met. A mix of life experience and youthful enthusiasm is often the best.

We are also aware of the high turnover in staff found in some care homes. This too is bound to work against efforts to build enduring relationships between residents and care staff.

2.3 Management understanding of dementia issues

If a care home sets itself up as providing care for people with dementia, it needs to be able to demonstrate its ability to do so. Managers must have the requisite training, experience and empathy to establish the right ethos and capability within the home. Again, based on calls to our advice line, we find that relatives find out too late that managers may not be up to the task. As the national dementia strategy points out, a majority of people living in care homes have some degree of dementia. It is essential that managers are

capable of establishing and maintaining a care regime that meets their needs.

In this, the regulator (currently CSCI, soon to be CQC,) has a role. In registering and thence inspecting a home, the regulator must be assured that the home can achieve what it claims to be able to provide. This requires deep knowledge and understanding of dementia issues on the part of the regulator (in order to be able to judge), not just on the part of the care provider. It starts with the environment – good design that meets standards established through research and responsive custom and practice – and goes on to training, staff ratios, appropriate recruitment procedures and staff supervision. The regulator needs to take all these factors into account at the point of registration and beyond.

2.4 Care regimes that foster good relationships between staff and residents

At the core of appropriate care provision for people with dementia, is the establishment of good relationships between staff and residents. This requires recruitment procedures that can identify the skills, empathy and experience required in prospective staff. It also requires skilled and experienced managers to enable and encourage good relationships to be built and fostered.

2.5 Involving relatives for insights about residents that may help their care management

Relatives can often help care homes in caring for their loved ones by providing insights into their past, into their current reactions and their wishes about preferred courses of action. Building good relationships with relatives can sometimes be difficult and it often needs time, skill and sympathy to do so. It is important to recognise the mixed emotions that relatives experience when a loved one with dementia goes into care. Managers play a key role in helping staff to handle this. Our experience based on calls to our advice line suggest that sometimes care homes reject relatives' wishes to continue to play a part in their loved ones' lives – to the detriment of all parties. Relatives for their part sometimes feel that the care home does not understand – and is unwilling to handle – their loved one's behaviour. In these situations, problems escalate and the resident can be required to move on to a different home. Relatives should be seen as key partners in the process of caring for residents, able to supply important information about an individual's past history that may contribute to a

better, deeper understanding of current behaviour and the steps that could be taken to respond effectively and appropriately.

2.6 Turning care plans into dynamic courses of action

Another concern based on the experience of families is the gap between what is set out in the care plan and what seems to happen in practice. Improving this, again, falls to management. The care plan isn't just a record for inspection purposes but a guide to the everyday care of the resident which also provides a basis for review and change as necessary.

This year's CSCI State of Social Care reports that 38% of care homes fail to reach national minimum standards in relation to care planning. In our experience, care homes are particularly poor in care planning for people with dementia. They fail to recognise the importance of person-centred care planning and its value in dementia care. We are concerned that CSCI inspectors lay down requirements on those care homes failing to meet the standards and yet do not follow up cases of repeated non-compliance.

2.7 Food and mealtimes – recognising the difficulties people with dementia have

Some of the biggest concerns of callers to the R&RA advice line in relation to dementia issues are those associated with food. Relatives are often worried by what they see as unnecessary sudden weight loss which they put down to the care home's neglect. The home must ensure that everything is done to assist residents to eat – by providing appropriate, appetizing food, giving them time and staff assistance to eat and drink and making mealtimes pleasurable occasions. This means ensuring that staff are trained to recognise, and meet, these needs. Just as important is the ability to recognise when to involve other skilled practitioners (dietitians, the GP, specialist dementia care practitioners) and to identify physical or psychological impediments to residents' ability or inclination to eat.

2.8 Recognition of depression

It is generally acknowledged that many people with dementia also suffer from depression but too often it is ignored and untreated. Staff need to be sensitive to this and be trained to identify signs and bring in the appropriate external skills to address this. Relatives are often worried by an obvious and significant deterioration in their loved ones' outlook which may well be caused by depression but feel powerless to intervene.

2.9 Involving external health services – GPs, nutritionists, dementia care

specialists, mental health teams

Staff need to know when to bring in external assistance – both practical support or advice. The national dementia strategy acknowledges this. However, in our experience (the R&RA is currently conducting a campaign to improve the health and wellbeing of care home residents) many homes find it difficult to engage with external health and social care services. Too often care home residents are seen as ‘out of sight, out of mind’ by local PCTs, GPs, and social services departments and, as a result, they fall to the bottom of the list of their priorities.

2.10 Better access to training

One of the biggest worries facing relatives in our experience is the perception they have that care home staff have not received proper training in the care of people with dementia. Training appears to be patchy, uncoordinated and non-mandatory. We firmly believe that dementia care should be a clearly specified requirement for managers and staff in any home that claims to be able to provide care for people with dementia. The extent of that requirement needs to be consulted on and nationally agreed and funded. In particular, small homes which are not part of larger provider organisations often fall outside current thinking about good practice. They need to be encouraged – and required – to get more directly involved.

3.0 Conclusion

The R&RA is pleased to have this opportunity to contribute to the APPGD Inquiry and hopes that its contribution will be fully considered. Older people with dementia living in care homes are a potentially very vulnerable group of people. Most are unable to act as their own witnesses effectively when poor practice, neglect and, at worst, abuse occurs. They need to be able to rely on a highly skilled, trained and empathetic workforce to ensure their interests and wellbeing are protected. We hope that the Inquiry will make a powerful contribution to ensuring this comes about.

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