



## All-Party Parliamentary Group on Dementia Inquiry Call for evidence

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### **The Relatives & Residents Association**

The Relatives & Residents Association (R&RA) exists to promote the rights and well-being of care home residents by providing advice and support to them, and their relatives, especially at times of crisis.

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

### **R&RA concerns about medication**

The R&RA is concerned about the inappropriate and excessive use of any medication and thinks that to focus solely on one type of medication overlooks some of the wider and equally important issues concerning medication for older people in care homes.

Adopting this wider perspective, we are particularly concerned:

- about the effects of polypharmacy which includes the way in which side effects from medication are masked or treated by other medication
- that sedating medication is used as a substitute for adequate numbers of, or adequately trained, staff
- that medication for residents in care homes is not consistently reviewed regularly or thoroughly enough as it should be in line with best practice and with the Regulations and standards
- that decisions around medication are not explained to relatives and friends sufficiently clearly or willingly by both medical practitioners and care staff.

We regard the inappropriate use of certain types of medication as constituting a dangerous form of restraint that can be physically damaging and life-shortening. We are concerned that systems and procedures to control the prescription of drugs to older people in care homes are inadequate because too often GPs fail to supervise or review decisions around such medication and, in many cases,

older people who are unable to consent to treatment and are therefore particularly vulnerable have no representative to act on their behalf. In many cases medication is prescribed as PRN – allowing the frequency and dosage to be varied at the discretion of staff without the GP having up-to-date knowledge of the patient concerned.

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## **1. How widespread is the use of antipsychotic drugs for people with dementia in care homes?**

As far as we are aware there is no accurate evidence to show the extent of the use (either appropriate or inappropriate) of anti-psychotic drugs for people with dementia in care homes as no organisation collects the data. Without a full, regular audit of how often anti-psychotic drugs are prescribed and the stated purposes for doing so, it is impossible to judge whether these drugs are being prescribed appropriately, why they are being prescribed and what approaches might be adopted to deal with the situations and circumstances. There is no reason why such data should not be collected. The law requires care homes to keep meticulous records on the use of drugs and these records are inspected by the Commission for Social Care Inspection (CSCI). Individuals' medication records are required to be reviewed regularly. Our concern is that this is not done. In response to the recent Panorama programme, *Please Look After Dad*, The Relatives & Residents Association called on CSCI to examine the use of anti-psychotic drugs in individual care homes in order to compare patterns of prescribing and administration and to monitor their use, thus helping to uncover potential misuses.

R&RA is concerned that CSCI's plan to inspect some care homes as infrequently as once every three years means that the care that individuals receive will be subject to even less professional scrutiny than is the case now.

## **2. Why are people with dementia in care homes being prescribed antipsychotic drugs?**

Unless drugs are being administered unlawfully, residents are being prescribed anti psychotic drugs by qualified professionals. Thus they have prime responsibility for both the initial decision to prescribe and its continuing review. Given the lack of reliable data on patterns of prescribing and the reasons for doing so, we regard it as impossible to judge why anti-psychotic drugs are prescribed apparently so readily. However the people who call our advice line about anti-psychotic drugs do so either because they are worried that drugs have been prescribed inappropriately, or they do not

understand why they should have been prescribed in the first place - they have been given little or no information about the drug and the reasons for prescribing it and do not see any benefit to their loved one, the patient/resident. GPs seem unwilling to discuss their prescribing practice for reasons of patient confidentiality, or because they disregard the importance of the close relationships between families and their loved ones.

In other cases, we are concerned GPs are prescribing drugs based on third-hand accounts of residents' symptoms or behaviour. If GPs base their decisions solely on representations from care home staff without examining patients directly, it raises the possibility of residents' symptoms being exaggerated by care staff in order to secure drugs to keep them subdued and easier to care for. This is a particular danger when a GP routinely takes on patients in a particular home (and is perhaps paid a retainer by the home) and has no prior knowledge of the individual resident.

A further concern for us is the possibility that drugs may be used because care homes don't have sufficient staff. One caller to our advice line was told recently by the manager of a care home that, if necessary, the home would arrange a "chemical straight jacket" for her mother. It would be easier, so it was argued, to sedate a resident than to provide the appropriate one-to-one care that was really needed.

### **3. To what extent is the use of these drugs appropriate?**

It is difficult to provide substantiated evidence but anecdotally our callers are describing situations where they are excluded from discussions about the medication prescribed to their loved ones, finding out about the drugs by chance, perhaps after asking care staff about changes in behavior, and are finding information about the drugs that have been prescribed by looking for information on the internet. This is completely unsatisfactory and leads to concern and suspicion.

### **4. What alternatives are there to the use of anti-psychotics?**

One of the main reasons why anti-psychotics are used inappropriately is because of misunderstandings of the behavior of people whose ability to communicate is impaired. Better training of care staff in the understanding of older people with dementia is part of the solution but a more systematic approach to decision making around invasive measures in whatever circumstances is needed. The inappropriate use of antipsychotic medication is, like locked doors, tags, bed rails and immobilizing furniture, a means of restraint and while restraint may sometimes be unavoidable, it must only be applied within clearly delineated circumstances, bound by

agreed protocols and procedures. It must be time-limited and regularly reviewed to ensure that the reason for its use remains and that the overall outcomes are the best for the individual patient. In too many cases older people in care homes are subject to measures that would be unacceptable in any other setting. We would like clear guidelines to help care homes make decisions that are the most effective, but the least invasive. Where homes fail to comply with these guidelines action should be taken to secure their compliance or to change their registration type – excluding them from looking after people whose needs they are unable to meet.

**5. What steps should be taken to ensure the appropriate prescription of antipsychotic drugs for people with dementia?**

- 1) Training for care staff must include strategies for dealing with challenging behaviour.
- 2) The drugs that are prescribed to individual residents must be reviewed regularly.
- 3) CSCI should collect and publish information on the level and type of prescription of medication in care homes.
- 4) The rights of relatives to be informed about what drugs are prescribed and why need to be made more explicit.
- 5) The regulatory authority must use sanctions against care homes found to be involved in the misuse of medication.

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