The use of antipsychotic medication for people with dementia:

Time for action

A report for the
Minister of State for Care Services
by
Professor Sube Banerjee

An independent report commissioned and funded by the Department of Health

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Letter to the Minister of State

Dear Minister of State

I was asked last year to examine the use of antipsychotic medication for people with dementia in the NHS in England, and this is my review.

There have been increasing concerns over the past years about the use of these drugs in dementia. The findings of my review confirm that there are indeed significant issues in terms of quality of care and patient safety. These drugs appear to be used too often in dementia and, at their likely level of use, potential benefits are most probably outweighed by their risks overall. This is a problem across the world, not one just restricted to the NHS. It is positive that, with action, we have the means with which to sort out this problem, quickly and safely.

Looking at the use of these drugs in dementia, it is clear that this is a specific symptom of a general cumulative failure over the years in our health and social care systems to develop an effective response to the challenges posed by dementia. So, it is positive that the National Dementia Strategy provides a framework for us to deal with the specific problem of the overuse of antipsychotic medication. As requested, this review presents clear, practical solutions.

In the course of this review, I have sought to understand the current evidence base, the law, and practice relating to prescription of these drugs in dementia. I have investigated the situation in other countries and sought the views of as many stakeholders as possible, including the public, people with dementia, carers, clinicians, NHS managers and the pharmaceutical industry, among others. This has taken place as part of the consultation and development process for the National Dementia Strategy and, following its publication, as a separate, specific line of enquiry.

Antipsychotic drugs are used for the management of behavioural and psychological symptoms in dementia. The development of such symptoms is a core part of the syndrome of dementia. They can cause major problems for people with dementia and their carers and are a legitimate focus for intervention to decrease distress and harm, and increase quality of life. However, the assessment and management of such behaviours in dementia can be complicated. The systems that we have for dementia treatment and care have grown by chance rather than by active planning or commissioning, and there are important gaps in services and skills. The consequence of this is that while some people

with dementia receive excellent care, for the large majority it appears that current systems deliver a largely antipsychotic-based response. Good practice guidelines are readily available but they do not appear to have been translated into clinical practice.

The evidence base includes gaps, contradictions and complexity but there is an emerging consensus with respect to the level of use and risk of antipsychotic drugs for people with dementia. There is uncertainty in any calculation where the data are incomplete, as in this case, and there is a need to be cautious about inferences made. However, reviewing the evidence, these drugs appear to have only a limited positive effect in treating these symptoms but can cause significant harm to people with dementia. Clearly, some people do benefit from these medications and there are groups (eg where there is severe and complex risk) where trials have not been completed but where there may be particular value in using these medications. Using the best available information, I estimate that we are treating 180,000 people with dementia with antipsychotic medication across the country per year. Of these, up to 36,000 will derive some benefit from the treatment. In terms of negative effects that are directly attributable to the use of antipsychotic medication, use at this level equates to an additional 1,620 cerebrovascular adverse events, around half of which may be severe, and to an additional 1,800 deaths per year on top of those that would be expected in this frail population.

Quality is the overarching principle for the NHS, with "quality at the heart of everything we do". *High Quality Care for All* stressed the importance of patient safety, stating that "…safety must be paramount for the NHS. Public trust in the NHS is conditional on our ability to keep patients safe when they are in our care". It is clear from this review that the current level of use of antipsychotics for people with dementia presents a significant issue in terms of quality of care, with negative impacts in patient safety, clinical effectiveness and the patient experience.

A positive finding of this review is that there are actions that we can take to address this problem. In doing so we would provide international leadership in this complex clinical area as well as improving the quality of life and quality of care for people with dementia and their carers in England. This report contains 11 recommendations that will, if implemented, reduce the use of these drugs to the level where benefit will outweigh risk and assure us that patients are being managed safely and effectively.

We need to make reduction in the use of these medications a clinical governance priority across the NHS, with strong national, regional and local leadership from the Department of Health, the Care Quality Commission, strategic health authorities, primary care trusts (PCTs), mental health trusts and acute trusts. We need a cycle of audit that will deliver good quality information on the use of these drugs in dementia and that can be used to drive down the use of these drugs in dementia safely and drive up the quality of initiation, monitoring and maintenance of these medications when they are needed. Leadership is

needed to enable the modest investment and service development needed to achieve this quality improvement.

I estimate that we can reduce the rate of use of antipsychotic medication to a third of its current level. I believe that it is realistic for us to seek to do this safely over a 36 month period.

At the heart of the action is the recommendation that each PCT should commission from specialist older people's mental health services a service that supports primary care in its work in care homes and the community. We will solve this problem by services working together, and there is need for extra capacity to enable a programme of in-reach work to all care homes with people with dementia resident and to GPs in the community. We can build on our existing nationwide network of specialist community older people's mental health services to deliver this.

To achieve and sustain this we also need to extend research on the clinical and cost effectiveness of non-pharmacological methods of treating behavioural problems in dementia and of other pharmacological approaches as an alternative to antipsychotic medication. Training and building skills are at the heart of the sustainability of this plan, and recommendations are made concerning improving the curriculum and skills in primary care and in care home settings, where a national vocational qualification in dementia is proposed.

I have tried to generate a broad practical plan of action with recommendations about how, on the balance of evidence, the Government should proceed. We can make these positive changes with a modest increase in investment coupled with re-designing existing structures to ensure that specialist input is available where needed into key decisions in care planning. I believe that the recommendations presented here offer a consistent, fair and affordable way forward.

I hope that the Government will feel able to accept and implement them.

Yours sincerely

Sube Banerjee
Professor of Mental Health and Ageing
The Institute of Psychiatry, King's College London

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Summary

1. Dementia is one of the most severe and challenging disorders we face. There are approximately 700,000 people with dementia in the UK; in 30 years, the number of people with dementia will double to 1.4 million. The national cost of dementia is about £17 billion per year; in 30 years, the cost will treble to over £50 billion.

2. The development of behavioural and psychological difficulties (eg agitation, aggression, wandering, shouting, repeated questioning and sleep disturbance) is common in dementia. These cause problems in themselves, which complicate care, and they can occur at any stage of the illness. They are a legitimate object for intervention to decrease distress and harm, and increase quality of life for the person with dementia and their carers. The systems that we have in place to manage behavioural problems in dementia have grown by chance rather than by specific planning or commissioning and there are important gaps in services and skills. Current systems appear to deliver a largely antipsychotic-based response. The first antipsychotic drugs were produced as a treatment for schizophrenia in the 1950s. This first generation is known as the 'typical' antipsychotics. This is to differentiate them from the 'atypical' antipsychotics, which became available from the 1990s. The atypical antipsychotics, have become much more commonly used than the typicals due to their favourable side effect profile. It is clear that these medications are being prescribed to deal with behavioural and psychological symptoms in dementia rather than just for psychosis.

3. The evidence includes gaps, contradictions and complexity but there is emerging consensus with respect to the level of use and risk of antipsychotic drugs for people with dementia. Reviewing the evidence, these drugs appear to have only a limited positive effect in treating these symptoms but can cause significant harm to people with dementia. However, some people do benefit from these medications and there are groups (eg where there is severe and complex risk) where trials have not been completed but where there may be particular value in using these medications. However, it appears that they are too often used as a first-line response to behavioural difficulty in dementia rather than as a considered second-line treatment when other non-pharmacological approaches have failed.

4. There is uncertainty about estimates of risk and benefit where the data are incomplete, and there is a need to be cautious about inferences made. However, on balance, it appears that around 180,000 people with dementia are treated with

antipsychotic medication across the country per year. Of these, up to 36,000 may derive some benefit from the treatment. In terms of negative effects that are directly attributable to the use of antipsychotic medication, use at this level equates to an additional 1,800 deaths, and an additional 1,620 cerebrovascular adverse events, around half of which may be severe, per year. The proportion of these prescriptions which would be unnecessary if appropriate support were available is unclear and will vary by setting, but may well be of the order of two-thirds overall.

5. The high level of use of antipsychotics means that the potential benefit of their use in specific cases is likely to be outweighed by the adverse effects of their use in general. This overuse of antipsychotic medication is a clear, specific example of the general set of problems in the way our health and social care systems serve people with dementia and their carers. We currently have systems that often work poorly; improving the quality of dementia services for all is the aim of the National Dementia Strategy and the findings of this review are complementary to its implementation.

6. Quality has been identified as the overarching principle for the NHS, with "quality at the heart of everything we do". *High Quality Care for All,* Lord Darzi's NHS Next Stage Review, stressed the importance of patient safety, stating that "…safety must be paramount for the NHS. Public trust in the NHS is conditional on our ability to keep patients safe when they are in our care". It is clear from this review that the current level of use of antipsychotics for people with dementia represents a significant issue in terms of quality of care, with negative impacts in its three main underpinning factors: patient safety, clinical effectiveness and the patient experience.

7. The review makes the positive finding that there are clear actions that can be taken to address this problem. In doing so we would be providing international leadership in this complex clinical area as well as improving the quality of life and quality of care for people with dementia and their carers in England. However, there are some simple actions which need to be avoided, such as prohibition or wholesale cessation of these medications. Such actions may themselves compromise patient safety, causing considerable harm and leading to a paradoxical increase in distress for people with dementia and their carers. A measured, planned approach is needed.

8. In this report there are 11 recommendations that will, if implemented, reduce the use of these drugs to the level where benefit will outweigh risk and where we can be assured that patients are being managed safely and effectively. Reduction in the use of these medications needs to be made a clinical governance priority across the NHS with strong national, regional and local leadership from the Department of Health, the Care Quality Commission, strategic health authorities, primary care trusts (PCTs), mental health trusts and acute trusts. We need a cycle of audit that will deliver good quality information on the use of these drugs in dementia and that can be used, over a

two-year period, to drive down the use of these drugs in dementia safely and drive up the quality of initiation, monitoring and maintenance of these medications where they are needed. This leadership is needed to enable the modest investment and service development needed to achieve this quality improvement. This means that decisive local action should be taken, using relevant local data on use of these drugs from the audit, to generate local goals and action planning.

9. A core recommendation is that each PCT should commission from specialist older people's mental health services a service that supports primary care in its work in care homes and the community. This will enable services to work together for the benefit of people with dementia and their carers. There is need for extra capacity in specialist dementia services that can work in all care homes where there are people with dementia and with GPs in these homes and in the community. We can build on the existing nationwide network of specialist community older people's mental health services to deliver this.

10. To achieve and sustain this we also need to extend research on the clinical and cost effectiveness of non-pharmacological methods of treating behavioural problems in dementia and of other pharmacological approaches as an alternative to antipsychotic medication. Training and building skills are of paramount importance in terms of sustainability of good practice, and recommendations are made concerning improving the curriculum and skills in primary care and in care home settings, where a national vocational qualification in dementia is proposed.

11. Making these changes will require modest extra investment in the system of dementia care; without this, the system will not be able to change to deliver the required quality improvements and improvements in patient safety identified. Throughout the review there was a clear message from clinicians, people with dementia and their carers, and commissioners alike that there was a need for an explicit vision of where we should aim to inform and invigorate local action. The following specific recommendations are made. These are presented in the order in which they appear in the structure of the text of the report. The order does not indicate priority – they should all be considered to have equal priority – neither does it indicate the sequence for their implementation.

Recommendation 1: Reducing the use of antipsychotic drugs for people with dementia and assuring good practice when they are needed should be made a clinical governance priority across the NHS. Using their existing clinical governance structures, Medical Directors (or their equivalent) in all primary care trusts, all mental health trusts and all acute trusts should review their level of risk in this area and ensure that systems and services are put in place to ensure good practice in the initiation, maintenance and cessation of these drugs for people with dementia.

Recommendation 2: National leadership for reducing the level of prescription of antipsychotic medication for people with dementia should be provided by the National Clinical Director for Dementia, working with local and national services. He or she should report on a six-monthly basis to the Minister of State for Care Services on progress against the recommendations in this review.

Recommendation 3: The National Clinical Director for Dementia should develop, with national and local clinical audit structures and leads, an audit to generate data on the use of antipsychotic medication for people with dementia in each primary care trust in England. This audit should be completed as soon as possible following the publication of this report, generating baseline data across England. It should be repeated one, two and three years later to gauge progress.

Recommendation 4: People with dementia should receive antipsychotic medication only when they really need it. To achieve this, there is a need for clear, realistic but ambitious goals to be agreed for the reduction of the use of antipsychotics for people with dementia. Explicit goals for the size and speed of this reduction in the use of antipsychotics in dementia, and improvement in their use where needed, should be agreed and published locally following the completion of the baseline audit. These goals should be reviewed yearly at primary care trust, regional and national level, with information published yearly on progress towards them at each level.

Recommendation 5: There is a need for further research to be completed, including work assessing the clinical and cost effectiveness of non-pharmacological methods of treating behavioural problems in dementia and of other pharmacological approaches as an alternative to antipsychotic medication. The National Institute for Health Research and the Medical Research Council should work to develop programmes of work in this area.

Recommendation 6: The Royal Colleges of General Practitioners, Psychiatrists, Nursing and Physicians should develop a curriculum for the development of appropriate skills for GPs and others working in care homes, to equip them for their role in the management of the complexity, co-morbidity and severity of mental and physical disorder in those now residing in care homes. This should be available as part of continuing professional development.

Recommendation 7: There is a need to develop a curriculum for the development of appropriate skills for care home staff in the non-pharmacological treatment of behavioural disorder in dementia, including the deployment of specific therapies with positive impact. Senior staff in care homes should have these skills and the ability to transfer them to other staff members in care homes. A national vocational qualification in dementia care should be developed for those working with people with dementia.

Recommendation 8: Each primary care trust should commission from local specialist older people's mental health services an in-reach service that supports primary care in its work in care homes. This extension of service needs the capacity to work routinely in all care homes where there may be people with dementia. They may be aided by regular pharmacist input into homes. This is a core recommendation of this report and it requires new capacity to be commissioned by primary care trusts in order that the other recommendations can be met.

Recommendation 9: The Care Quality Commission should consider using rates of prescription of antipsychotic medication for people with dementia, adherence to good practice guidelines, the availability of skills in non-pharmacological management of behavioural and psychological symptoms in dementia and the establishment of care home in-reach from specialist mental health services as markers of the quality of care provided by care homes. These data should be available by analysis of local audit data and commissioning decisions.

Recommendation 10: The Improving Access to Psychological Therapies programme should ensure that resources are made available for the delivery of therapies to people with dementia and their carers. Information and support should be available to carers to give them the skills needed to spot behavioural problems quickly, to seek help early and to deploy elements of non-pharmacological care themselves in the home.

Recommendation 11: Specialist older people's mental health services and GPs should meet in order to plan how to address the issue of people with dementia in their own homes who are on antipsychotic medication. Using practice and patient-level data from the completed audits on the use of these medications, they should agree how best to review and manage existing cases and how to ensure that future use follows best practice in terms of initiation, dose minimisation and cessation.