



All-Party
Parliamentary Group
on Dementia

Always a last resort

**Inquiry into the prescription of
antipsychotic drugs to people with
dementia living in care homes**

April 2008

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Foreword

One in three people over 65 will end their lives with dementia and millions more among our families and friends will be affected through providing care and support. There is currently no cure, and only limited treatments, so management of the condition should be of great concern to all of us. Two-thirds of care home residents have a form of dementia, and it is those people who are the subject of this report.

In a care home setting, the management of dementia presents particular challenges. We should appreciate the pressures on those people who provide care but we must not accept swift resort to inappropriate chemical restraint when better care is needed. In the course of this inquiry, it has become clear that the over-prescription of antipsychotic drugs to people with dementia in care homes is a huge problem. It may arise from inappropriate prescriptions, or from a prescription which is initially justified but which continues for too long, and it does significant harm. It may damage physical well-being, compromise dignity and infringe human rights. It is systematic abuse of people with dementia in care homes.

This report does not just state the problem, but also proposes what we believe to be some workable solutions. It has been produced to inform the National Dementia Strategy for England, which will be published later this year.

The Care Services Minister has indicated his intention to bring dementia out of the shadows. In exploring the use of the wrong drugs for the wrong reasons for people with dementia in care homes, this report seeks to shine a light into one of the darkest corners of dementia care and in doing so to improve the lives of some of the most vulnerable in our society.

A handwritten signature in black ink that reads "Jeremy Wright". The signature is written in a cursive, slightly slanted style.

Jeremy Wright MP
Chair, All-Party Parliamentary Group on Dementia

All-Party Parliamentary Group on Dementia

The All-Party Parliamentary Group (APPG) on Dementia, chaired by Jeremy Wright MP, was created to build support for dementia to be a publicly stated health and social care priority in order to meet one of the greatest challenges presented by our ageing population.

The inquiry

In November 2007 the APPG on Dementia announced that it would be undertaking an inquiry into the prescription of antipsychotic drugs to people with dementia in a care home setting. The APPG conducted this inquiry because of concerns expressed by carers, patient organisations and academics about the appropriateness and safety of prescribing antipsychotic drugs to people with dementia.

The inquiry requested evidence from a variety of stakeholder groups including people with dementia, carers, health and social care professionals, care home providers, academics, regulators and trade bodies. These organisations and individuals were invited to submit views on the following issues:

- How widespread is the use of antipsychotic drugs for people with dementia in care homes?
- Why are people with dementia in care homes being prescribed antipsychotic drugs?
- To what extent is the use of these drugs appropriate?
- What alternatives are there to the use of antipsychotics?
- What steps should be taken to ensure the appropriate prescription of antipsychotic drugs for people with dementia?

The Group also heard evidence from key organisations and individuals in two oral evidence sessions held at the House of Commons on 4 and 5 February 2008. These sessions were overseen by Jeremy Wright MP, Baroness Greengross, Gordon Marsden MP, David Taylor MP, Baroness Thomas and Betty Williams MP.

Witnesses

Dr David Anderson Chair, Faculty of Old Age Psychiatry	Royal College of Psychiatrists
Dr Graham Stokes Consultant Clinical Psychologist, Head of Mental Health	BUPA
Ms Emma Bryer Care Home Manager	Barchester Care Homes
David Walden Director of Strategy	Commission for Social Care Inspection
Hazel Sommerville Head Pharmacist	Commission for Social Care Inspection
Dr Andy Barker Consultant Old Age Psychiatrist and Clinical Adviser to the Healthcare Commission	Hampshire Partnership Trust
Professor Clive Ballard Director of Research	Alzheimer's Society
Cheryl Bryne Carer	
Dr Jane Fossey Consultant Clinical Psychologist	Oxfordshire Health Care Trust
Dr Dan Nightingale Senior Dementia Consultant	Southern Cross Healthcare

Acknowledgements

The Group would like to thank the Alzheimer's Society for its assistance in organising the oral evidence sessions and with the writing of this report. We would also like to thank the witnesses who took part in the oral evidence sessions, as well as those individuals and organisations that submitted written evidence.

Inquiries

Please direct any comments or queries that you may have about this report or about the Group to the Secretariat at appg@alzheimers.org.uk or alternatively contact the Chairman, Jeremy Wright MP, at the House of Commons, London, SW1A 0AA.

Summary

In this report the All-Party Parliamentary Group on Dementia examines the use of antipsychotics for people with dementia in care homes.

The Group heard that over-prescribing is clearly a significant problem in many care homes (paragraphs 11–15). Evidence submitted to the inquiry highlights specific reasons for the use of antipsychotics. These drugs are prescribed as a response to the behavioural and psychological symptoms of dementia, experienced as a result not only of the condition, but also as a result of a wider and more complex set of problems external to the individual's condition (paragraph 18).

These problems include a lack of dementia care training for care home staff, which results in the staff not being able to support people with dementia, for example by providing person-centred care. Further problems include inadequate leadership in care homes, a lack of support from external services (including inadequate monitoring and review of prescriptions) and the exclusion of family and friends from decision-making (paragraphs 19–50).

There are serious concerns that there is widespread inappropriate prescribing, for example, antipsychotics are being used for people with dementia who have mild behavioural symptoms and prescribing is often continued for long periods of time (paragraphs 61–66). This is despite the fact that antipsychotics have limited benefit for people with dementia, particularly when prescribed for long periods, and despite the serious side effects associated with their use (paragraphs 54–56).

Side effects include excessive sedation, dizziness and unsteadiness, which can lead to increased falls and injuries, as well body rigidity and tremors. Research shows that there is almost a doubling in the risk of mortality and an increase the risk of stroke by up to three times.

These side effects can be very harmful and can rob people with dementia of their quality of life. The widespread inappropriate prescribing of antipsychotic drugs is an unacceptable abuse of the human rights of people with dementia.

The Group found that in specific circumstances the use of antipsychotic drugs can be appropriate. The Group recommends that the use of antipsychotics should always be a last resort, used at times of severe distress or for critical need (paragraphs 51–53).

There are good practice guidelines, for example the National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (NICE-SCIE) guideline (2007), that set out effective and appropriate guidance on

pharmacological and non-pharmacological solutions. However, the barriers to this good practice being implemented, such as a lack of training and lack of support from external services, means the current system does not enable or support this good practice on a wide scale. There is an urgent need to address these barriers (paragraphs 57–60).

In addition, in the Group's view there are alternatives and solutions to the use of antipsychotics, which some care homes have employed to good effect and which should be widely used. Many of these are small-scale, simple solutions, which could be implemented immediately, such as having an individually tailored care plan (paragraphs 69–76).

The Group makes recommendations to ensure the appropriate prescription of antipsychotic drugs to people with dementia in care homes and to ensure that alternatives to the drugs are available and implemented. The overall recommendation is that the National Dementia Strategy for England must include an action plan to reduce the number of prescriptions. Specific recommendations are as follows:

- Dementia training should be mandatory for all care home staff (paragraphs 77–84).
- Care homes must receive effective support from external services, including GPs, community psychiatric nurses, psychologists and psychiatrists, which should involve regular, pro-active visits to the care home (paragraphs 85–87).
- The use of antipsychotics for people with dementia must be included in Mental Capacity Act training for all care home staff (paragraphs 88–91).
- Protocols for the prescribing, monitoring and review of antipsychotic medication for people with dementia must be introduced (paragraphs 92–100).
- There should be compulsory regulation and audit of antipsychotic drugs for people with dementia (paragraphs 101–106).

Introduction

The inquiry

1. The number of people with dementia in the UK is growing. 700,000 people in the UK have dementia and this is forecast to increase to 940,000 by 2021 and 1,735,087 by 2051, an increase of 38 per cent over the next 15 years and 154 per cent over the next 45 years.
2. Whilst the prescription of antipsychotic drugs for people with dementia applies in all healthcare and community settings, we chose to limit our inquiry to care homes. This is because evidence shows that there are particular concerns about the widespread prescribing of the drugs in this setting. Two thirds of care home residents have some form of dementia (244,000 people) and the proportion of residents with dementia is likely to increase as people with lower level needs are supported to live at home.
3. Antipsychotic drugs are prescribed to people with dementia in response to behavioural and psychological symptoms. The drugs were developed to treat the psychotic symptoms associated with schizophrenia and they are not licensed to treat the behavioural symptoms of dementia. However, doctors are free to prescribe licensed drugs outside the parameters of the licenced a product (off-licence prescribing) and antipsychotic drugs are widely used for people with dementia. There are two types of antipsychotic drugs frequently prescribed to people with dementia – typical (older drugs such as haloperidol and chlorpromazine) and atypical (newer drugs such as risperidone, olanzapine, quetiapine and amisulpiride).¹
4. There are concerns around the appropriateness and safety of prescribing antipsychotic drugs to people with dementia. Antipsychotics have limited benefit for people with dementia, particularly when prescribed for longer than 12 weeks, and there are serious side effects associated with their use. These can be very harmful and can rob people with dementia of their quality of life.
5. Side effects include excessive sedation, dizziness and unsteadiness, which can lead to increased falls and injuries, as well as parkinsonism (tremors and rigidity), akathisia (body restlessness), reduced well-being, social withdrawal, accelerated cognitive decline and severe sensitivity reactions.

¹ Atypical and typical drugs both cause side effects such as Parkinsonism and body restlessness. However, these side effects may be less frequent in atypical drugs.

6. Recent work has highlighted the seriousness of these side effects. Research shows that there is almost a doubling in the risk of mortality (Food and Drug Administration 2005) and, in March 2004, the Committee on Safety of Medicines decided that the atypical antipsychotic drugs risperidone and olanzapine should not be used for the treatment of behavioural symptoms in people with dementia because they increase the risk of stroke by up to three times.
7. The concern that antipsychotics are widely prescribed to people with dementia in care homes, despite these dangerous side effects and risks, made it vital that an inquiry into the use of antipsychotics was conducted. The widespread inappropriate prescribing of antipsychotic drugs is an unacceptable abuse of the human rights of people with dementia, robbing thousands of people of their quality of life.

Structure of the report

8. In section 1 we set out the evidence we received on the scale of the prescribing of antipsychotics to people with dementia in care homes. Section 2 explains why people with dementia are being prescribed antipsychotic drugs and in section 3 we consider the extent to which the use of these drugs is appropriate. In section 4 we explore the evidence on what can be done to limit the use of antipsychotics. Finally, in section 5, we set out our conclusions and recommendations.

Evidence

9. We have received over 70 written evidence submissions from organisations and individuals, and we heard key evidence in two oral evidence sessions. Most of this evidence is published in full in a separate report.
10. All the evidence was collated and the key messages extracted. These key messages form the basis of the report and are grounded in examples, with the use of verbatim extracts and written evidence to support the argument being made. The report also points to key research evidence where appropriate.

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

11. The oral and written evidence is in clear agreement that there is widespread use of antipsychotics in care homes for people with dementia. For example, the British Medical Association, the Royal College of Psychiatrists, the Commission for Social Care Inspection (CSCI), the Royal College of General Practitioners, Alzheimer's Society, Action on Elder Abuse, BUPA, Southern Cross Healthcare and individual submissions from carers and professionals all point to this. In his oral evidence witness Professor Ballard estimated that:

'Probably from the best estimates there are somewhere between 100,000 and 150,000 people in the UK in care facilities, with dementia, who are prescribed these treatments.' (Ballard, 5 February, oral evidence)

12. The Alzheimer's Research Trust refers to research (Allred et al 2007), which found that of 331 residents studied, 67 (20 per cent) were prescribed an antipsychotic. The prescribing rate was 32 per cent (46 out of 146) for those with dementia and 10 per cent (17 out of 174) for those without dementia. A witness said:

'I would say that of the last 30 residents I have assessed over the last two years the majority were on antipsychotic medication and I would estimate that over 50 per cent of dementia clients within care homes are on antipsychotic medication.' (Bryer, 4 February, oral evidence)

13. It was found that whilst research and experience clearly show how widespread the problem is, there has not been an audit of the scale of the problem. This would be welcomed by many organisations. In its written submission, CSCI summarise the situation:

'It is not part of CSCI's role to systematically collate information about clinical diagnoses or which medicines are prescribed for people who live in care homes. The appropriateness of clinical and prescribing decisions is subject to governance procedures in the NHS and therefore comes within the scope of the Healthcare Commission's monitoring functions. However, neither regulator is able to detail the nature and extent of antipsychotic

prescribing for dementia in care homes, which would require a prevalence study. CSCI would welcome such a study undertaken by an academic or research body.'

14. Submissions also noted that we must be aware that good practice does exist in some care homes. The organisation For Dementia highlights that Admiral nurses gave a mixed response to the question of how widespread the prescription of antipsychotics is, suggesting that the picture is varied. Dr Nori Graham, an emeritus consultant in old age psychiatry, also notes this variation and suggests that this is due to differences in the quality of care:

'I have visited homes where virtually all people with dementia are on these drugs and others where less than 10 per cent are on medication. I am in no doubt that low levels of use of antipsychotic medication are an indication of better care.'

The submission of a carer of a person with dementia provides an example of this good practice:

'My mother had bad hallucinations and was prescribed haloperidol by the hospital consultant, while she was living on her own. When she went into a care home, the prescription for this drug was stopped as I was told mum was now receiving 24/7 care so it wasn't necessary.'

Conclusion

15. **The Group concludes that there is a consensus among patient and professional organisations, the regulators and the care home sector that over-prescribing antipsychotics is clearly a significant problem. We note that evidence of good practice in some care homes is also available.**

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

16. Below we explore the evidence on why people with dementia in care homes are being prescribed antipsychotic drugs. There is consensus from the oral and written evidence on the key problems, which can lead to care homes resorting to the prescription of antipsychotics.

- A response to the assumed behavioural and psychological symptoms of dementia, which can be an expression of unmet needs, for example due to a poor environment in the care home.
- Issues with inadequate leadership, lack of dementia care training for care home staff and low staffing levels.
- Lack of support from external services such as general practitioners (GPs) and older people's mental health teams.
- People with dementia, carers and relatives being excluded from prescribing decisions, for example by the GP.

The following evidence from witnesses provides a summary of why antipsychotics might be prescribed:

'Within the care home environment staff are faced daily with situations which are physically and emotionally challenging and when they see no other way they will liaise with the GP to have antipsychotic medication prescribed.' (Bryer, 4 February, oral evidence)

'If we lived in a better world these drugs would not be a default position, which sometimes they are at the present time, because we would have better environments, better informed care, better approaches to offer some people who get these drugs now by default.' (Anderson, 4 February, oral evidence)

17. The submission from the Royal College of Psychiatrists draws attention to the recent *Home from Home* report (Alzheimer's Society, 2008). The findings from this report on the quality of care in care homes relate closely to the problems identified in this inquiry:

'The recent report from the Alzheimer's Society (2008) draws attention to the range and common nature of deficiencies in care home practice that is

relevant to this analysis. In this report care staff identified understanding and managing difficult behaviour to be the most difficult part of caring for people with dementia. It is likely that some drugs are prescribed as a poor substitute for a rich and stimulating environment, adequate numbers of care staff and better training.'

Conclusion

18. **In our view the evidence builds a picture of behavioural symptoms, experienced as a result not only of the condition, but also as a result of a wider and more complex set of problems external to the individual's condition. Antipsychotics are prescribed, often as a first resort, as a quick and accessible way of managing these behavioural symptoms, such as aggression, shouting and restlessness.**

We will now look at the key problems in some detail.

Behavioural and psychological symptoms of dementia (BPSD)

19. Evidence suggests that antipsychotics are often prescribed as a treatment for what are considered the behavioural and psychological symptoms of dementia. For example, Alzheimer's Society, the British Medical Association (BMA), For Dementia (Admiral Nurses), Southern Cross, the Royal College of Psychiatrists, the Commission for Social Care Inspection (CSCI), consultants in old age psychiatry, Alzheimer's Research Trust, BUPA, Age Concern England and carers all highlight the role of the behaviour of the person with dementia in the prescription of antipsychotics. The Royal College of Psychiatrists gives examples of these symptoms:

'The term BPSD includes a range of abnormal experiences (like hallucinations, depression) and aberrant behaviours (like aggression, agitation, dis-inhibition, shouting, over-activity) which are very different and will have different causes in different individuals and different meaning at different stages of the disease.'

20. Research evidence shows that more than half of all people with dementia experience behavioural and psychological disturbances at any one time as part of their condition (Ballard, Waite and Birks 2006). Behavioural and psychological symptoms are particularly common in people with dementia living in care homes. Margallo-Lana et al (2001) found that more than 70 per cent of residents had clinically significant symptoms.
21. Evidence from individual carers confirms that antipsychotics have been prescribed to a person with dementia in response to challenging behaviour.

This evidence also highlights that antipsychotics can be prescribed for behaviour that, although important, is not causing extreme distress or risk to the individual or staff and other residents, such as restlessness or being vocal.

‘His GP referred him to a consultant psychiatrist who prescribed him haloperidol. This was because he was increasingly wandering about.’

And:

‘My mum was prescribed this as she was very agitated and very vocal.’

And:

‘He was prescribed antipsychotics initially in a home that found it difficult to cope with his condition.’

And:

‘Sleeplessness and persistent shouting have been a problem.’

22. The Group also heard that some challenging behaviour, such as aggression, can have more serious consequences for care home staff and residents. This behaviour can present a risk to the individual, care home staff and other residents, and can lead to difficulty in care home staff being able to manage the personal care of residents.

‘Published only very recently, in the last week or so, has been a national audit of violence, not in care homes but in mental health wards. When they looked at the older people’s wards the rates of violence were higher than they were in the working age adult mental health acute wards. I think we have to realise this. Older people’s problems are not trivial. Some of these behaviours can be seriously dangerous to themselves, to other residents, to carers, to family, and they are awful things to see.’ (Stokes, 4 February, oral evidence)

‘I think abuse is an issue because people with dementia do refuse personal care and this is a fundamental human need. If the person is refusing and the staff do not carry out the care it could be considered neglect. However, if the person is refusing and they carry on regardless it could be considered physical abuse. Medication does make people more passive and compliant.’ (Bryer, 4 February, oral evidence)

Conclusion

23. **The Group agrees with submissions highlighting that it is important not to trivialise some of the challenging behaviour shown by people with dementia in care homes, such as aggression, which can have serious consequences. However, antipsychotics can also be prescribed for behaviour that is not causing such extreme distress or risk, such as restlessness or being vocal.**

BPSD as an expression of unmet needs

24. However, evidence shows that BPSD is not only a symptom of dementia, but is also an expression of the unmet needs of an individual (as agreed, for example, by the Royal College of Psychiatrists, the Royal College of Nursing, CSCI and Alzheimer's Society). BUPA raises the question of whether these are actually symptoms at all:

'A paradigm shift has been evolving over the past 20 years wherein behaviours that challenge are understood not as symptoms of brain pathology but as evidence of people with dementia trying to communicate their needs and reacting to the quality of life they receive.'

25. The Royal College of Nursing estimates that only 10 per cent of challenging behaviours occur as a consequence of dementia with 90 per cent occurring in response to care practices or environmental factors. They suggest that a 'diagnostic overshadowing' occurs leading to all challenging behaviours to be solely attributed to brain damage, which overshadows anything else a person with dementia may present with.

26. The evidence suggests that these unmet needs could be due to several factors. For example, the evidence submission from Dr Nori Graham, consultant in old age psychiatry, stated that:

'Assessment may reveal a physical problem eg a urinary tract infection or deafness. It may also reveal affective symptoms eg depression or anxiety. These symptoms need appropriate and active treatment and the person's difficult behaviour will improve.'

27. Alzheimer's Society points to research that shows that the day-to-day environment of the care home is an important factor:

'The day-to-day environment of the care home can significantly affect outcomes for residents. In particular, inactivity and low levels of engagement have been found to contribute to behavioural symptoms, as well as loss of physical function, social isolation, and poor quality of life. (Mor, Branco, Fleishman et al 1995; Alessi, Yoon, Schnelle et al, 1999)'

Conclusion

28. **The Group concludes that the behavioural and psychological symptoms of dementia can be an expression of need. There is a concern that care homes resort to the use of antipsychotics as a solution to this behaviour, when in fact these symptoms are caused by unmet needs that require different solutions, such as a person-centred approach to care or a rich care home environment that provides activities and opportunities for social interaction.**

Issues around training, staffing levels and leadership

29. The evidence shows that inadequate training of care home staff, high staff turnover, and poor leadership in care homes also have a role in care homes resorting to the prescription of antipsychotics.

Inadequate staff training in dementia care

30. There are currently inadequate numbers of staff in care homes who are well-trained in supporting people with dementia, for example giving person-centred care, understanding challenging behaviour and communicating with people with dementia. Dementia training is not currently a requirement and many staff do not have qualifications in dementia care.

Witnesses said:

‘We give people in care homes one of the most complex conditions in medicine to manage and we give them no training whatsoever on how to do it.’ (Anderson, 4 February, oral evidence)

And:

‘Dementia care training itself comes as a low priority; mandatory training – fire training, moving and handling training – all those other mandatory training courses come far above person-centred care training in the homes.’ (Nightingale, 5 February, oral evidence)

And:

‘I think independent care home managers are under constant pressure to increase their occupancy and that often becomes the main focus, increasing occupancy, and they will accept people into the homes when the staff are not trained or able, they have not got the knowledge, skills or competencies to meet that individual’s needs, so there is that issue.’ (Nightingale, 5 February, oral evidence)

31. A lack of training in dementia means that care home staff may not be able to recognise dementia and understand an individual’s needs resulting from this condition. This can be a real problem if the dementia has not been diagnosed when an individual enters the home or if they go on to develop dementia. The issue of under-recognition is highlighted in the evidence from Dr Nori Graham, consultant in old age psychiatry:

‘Not uncommonly antipsychotic drugs are inappropriately used for disturbed behaviour as a result of a failure to diagnose dementia. Once staff realise that dementia is present they make allowances for the patient’s memory loss with resulting improvement in behaviour.’

32. The Registered Nursing Home Association states that the recognition and diagnosis of dementia is essential before an appropriate care plan can be drawn up, agreed and put in place. A care plan would help staff to provide good quality care, tailored to the needs of the individual. Both Action on Elder Abuse and Age Concern England suggest that care plans should be regularly reviewed. Without a care plan, which would suggest appropriate alternatives for the individual, and training to allow staff to implement these alternatives, antipsychotics are likely to be used as a 'quick fix'.
33. It is important to note that it is not just care home staff that may be lacking in training. The BMA submission admits that there has been relatively little postgraduate education for GPs on the use of these drugs in the complex dynamic of an elderly care home. GPs therefore may not know when it is appropriate to prescribe antipsychotics and what alternatives are available:

'One of the main problems doctors face are the limited options available to manage patients with dementia.'

And as one GP stated in their individual submission:

'I am a GP who acquired lots of dementia residents in long stay care recently, and was totally bewildered by the limited options available to me.'

High staff turnover

34. There are other challenges to providing good dementia care in care homes. Skills for Care highlights that high staff turnover is an issue for the social care workforce, with turnover at about 13 per cent. However, they suggest that such data can disguise regional variation, with some areas such as London and the South East having particular difficulties.
35. The NICE-SCIE clinical guideline (2007) identifies that staff shortages and pressures affect care. They highlight that managing risk is often all staff have time for when staffing levels are low. This is evident from the submission by a social worker:

'These drugs are often not used to alleviate suffering for the residents but to make up for inadequate staff levels in care homes, especially at night.'

Inadequate leadership from care home managers

36. As well as ensuring an adequate number of staff with training in dementia care, it is important to ensure that the staff are supported and encouraged to implement new ways of working. Effective leadership is needed for this

as it helps to set the tone and culture of the care home. Witnesses highlighted the need to improve the leadership within care homes:

‘I would be very keen to see specialist leadership training within homes because without that being specifically for care homes we are not going to get the career structures and the people who are leading that cultural change who are going to ensure supervision and the clinical practice is there in the first place. People may have good nursing training; that does not necessarily mean that they are good leaders.’ (Fossey, 5 February, oral evidence)

‘We also put a lot of store by the leadership qualities of the managers of these care services which colleagues have talked about. We think that is a really important indicator and driver of quality, if you like, but often these are quite small services, certainly compared to NHS hospitals, and the quality of the leadership of those services is absolutely critical to the quality of care provided and the way people are looked after. We would like to see some emphasis on that.’ (Walden, 4 February, oral evidence)

Conclusion

37. **The Group concludes that a lack of dementia care training for staff, a high staff turnover and inadequate leadership in a care home setting can partly explain the use of antipsychotics. With little time or training to implement appropriate alternatives, care homes may look to a ‘quick’ and more accessible method of managing behaviour.**

Lack of support from external services

38. Much of the evidence suggests that support provided by external services, such as GPs and older people’s mental health teams, varies considerably. For example, Alzheimer’s Society’s Home from Home report (2008) found that one third of care home managers reported no support or very limited support from the local older people’s mental health service and one quarter of them listed accessing advice from external services as one of the top three challenges in providing good dementia care.
39. Alzheimer’s Society also refers to The National Audit Office report *Improving services and support for people with dementia* (2007), which found that the majority of community mental health teams did not have formal outreach with care homes. One witness said:

‘Specialist services, from my perspective, are increasingly overstretched because they have had a gradual leakage of funding from them, so we have gradually become more and more consultative. We go in, see a problem,

advise, withdraw again, and when you go into a care home that is not coping with somebody then you have options about trying to get the care home to completely change their environment, trying to get the care home to train their staff better or using one of these medications in the short term to help with something like severe agitation or aggression.’ (Barker, 5 February, oral evidence)

Evidence submissions also describe the problems. For example, the submission from a GP stated that:

‘They [psychogeriatricians] are few and far between, and can be very good – and can be worn into the ground. We have just changed to a new one, who seems to be very good, but my previous experience consisted of asking for help and advice from ‘the experts’ and getting back, predictably, advice to sedate – with anything... and if the patient declines to take it, to give the medication covertly.’

And the BMA noted that:

‘Faced with a patient with challenging behavioural problems, especially unprovoked physical aggression as opposed to resistance to personal care, which needs to be addressed as a matter of urgency, it can be difficult to access even specialist telephone advice immediately and very difficult to get an urgent domiciliary assessment by a specialist to assess such an individual (on the day, before a night where the risks to staff and other residents are generally greater) by a specialist in elderly psychiatry, depending on where in the country a doctor is working.’

A submission from a carer shows how a person with dementia can be affected by the lack of support from external services:

‘My wife is resident in a nursing home and last year the GP started prescribing all types of drugs until one day the home sent for me because she had deteriorated rapidly. We eventually got the GP out and he admitted that he did not know what to do. He suggested that he should ask the consultant to visit and see what he could do to help my wife. It took five months to get him to visit the home by which time my wife’s health deteriorated. When he saw what medication she was on he immediately arranged to have her taken off all antipsychotic drugs. This is now being done but will take several months to complete.’

40. Many organisations and individual submissions note that a prescription may have been made before the person with dementia entered the care home, particularly when living in the community or having entered hospital. For Dementia states that this prescription may then continue when the individual

enters a care home due to a lack of follow up and assessment by knowledgeable professionals.

41. It is also important to note that a lack of support from external services can lead to the person with dementia remaining on antipsychotics for long periods of time, due to inadequate monitoring and review. This means that prescriptions are not discontinued once they are no longer benefiting the person with dementia (paragraph 66).
42. There is evidence showing that once people are on medication, they stay on it because of inadequate management and review of medication. The Alzheimer's Research Trust points to research that found that of 331 elderly residents, only a quarter (82 out of 331) had received a medication review by the general practitioner in the preceding 12 months (Alldred et al 2007). Evidence also comes from carers:

'Mother was also prescribed amisulpride which is licensed only for schizophrenia (which my mother did not suffer from), and which should only be used with caution in the elderly. She was prescribed this drug for aggression only three days after having a grand mal seizure. Although the drug should be used with caution in the elderly and where there is an history of epilepsy, the consultant prescribed 120 doses even though she was not to see my mother again for another 6 months, leaving unqualified care staff to routinely administer the medication unmonitored, without realising the potential side effects.'

Conclusion

43. **The Group concludes that if care homes had better support from external services this would improve the quality of care provided in the care home. The use of antipsychotic drugs would be reduced by cutting down on the number of new prescriptions and ensuring the appropriate discontinuation of current prescriptions through adequate monitoring and review.**

The exclusion of people with dementia and carers from the decision-making process

44. Many evidence submissions highlighted the problem of the exclusion of carers from the decision-making process regarding the use of antipsychotics, despite consultation being a key component of the Mental Capacity Act (paragraph 47). One witness described this:

‘There is therefore a kind of collusion, I think, where the care homes are happy because the person with dementia is now not causing them so much trouble, the GP is happy because they do not have to keep going back, the specialist may advise review but often does not, does not get called back in again to see the person, families may be aware that someone has gone on medication or may not be, but they are by and large happy that the problem seems to have gone away, that things have settled and therefore the person can carry on living there.’ (Barker, 5 February, oral evidence)

CSCI explain in a written evidence submission how this collusion may lead to the prescription of an antipsychotic:

‘It is possible a care worker may exaggerate the problems to make sure that a prescription for antipsychotic drugs is provided by the GP.’

45. This is a key concern for carers and relatives. The Relatives and Residents Association stated that many of the calls to its helpline are from people who have been given little or no information about antipsychotic drugs or the reasons for prescribing them and do not see any benefit to the care home resident. This leads to concern and suspicion among carers and family members, and feelings of helplessness and being uninformed. Carers said:

‘We were not aware that this antipsychotic drug had been prescribed as no one had informed us. Unaware that mum was on the drug, we were unable to read up on it and be aware of its possible side effects.’

And:

‘No clarity on what we as carers should look out for, for example, how do we know which side effects are specifically caused by the antipsychotic drugs and not dementia?’

46. The Group is aware that the care home may also be excluded from decisions:

‘GP prescribed increased dose. Care home manager is extremely upset about the situation and the increased dose of quetiapine. The increase was made by phone without a visit from the GP.’ (Carer)

And that in some instances good practice does exist:

‘The care home has been marvellous in all areas regarding my mum’s health and well-being. They liaise with the family regularly and I read and sign her progress reports monthly raising issues as and when I feel the need. I am always listened to and a positive response has been forthcoming.’ (Carer)

The Mental Capacity Act (2005): lack of understanding

47. Part of the problem is a lack of understanding and implementation of the Mental Capacity Act. As Age Concern England state:
- ‘There does not appear to be a detailed understanding of the practical application of the Act’.
- ‘Not all care home managers have full understanding of the Act and how it works and the impact and how to implement it.’ (Nightingale, 5 February, oral evidence)
48. According to the Act decisions must be made in the best interests of the individual with dementia, and people such as carers or independent advocates should be consulted, and this is often not happening. One GP describes how decisions can often be made in the best interests of the relatives rather than the person with dementia:
- ‘At least if the behaviour is quiet then we help the relatives. There is no other drug to help – and we try not to be helpless. When we can do nothing else we try and relieve suffering – in this case the suffering of the relatives.’
49. The Relatives and Residents Association also points out that 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. There is therefore a need for independent advocates. When giving evidence, Professor Ballard also mentioned the need for making an advance decision, which enables adults to refuse in advance a specific medical treatment or procedure should they become unable to decide for themselves in the future. Age Concern England also highlights that the Mental Capacity Act makes provisions for advanced decisions. Considering these issues would ensure that the voice of the person with dementia and their wishes are taken into account.

Conclusion

50. **The Group concludes that people with dementia and carers are being excluded from decision-making, despite this being a requirement of the Mental Capacity Act. This allows care homes and external services in some instances to prescribe without having to fully assess and discuss the situation, such as the risks and benefits of the drugs.**

3. To what extent is the use of antipsychotic drugs appropriate?

When is prescribing appropriate?

51. Summarising the evidence has brought the Group to the conclusion that the prescription of antipsychotic drugs is appropriate for people with dementia in care homes in very specific situations (paragraphs 52–54). Many organisations and individuals, for example Action on Elder Abuse, Age Concern England, the Dementia Research Centre, Royal College of Psychiatrists, the Royal College of General Practitioners, the Alzheimer’s Research Trust and consultants in old age psychiatry agree that it can be appropriate but only in particular situations.

52. Oral and written evidence submissions point to the National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (NICE-SCIE) clinical guideline (2007) as confirmation of this (paragraphs 57–59). The NICE-SCIE guideline suggests that antipsychotic drugs should be used in the first instance only if an individual is severely distressed or if there is an immediate risk of harm to others. If distress and/or agitation are less severe, non-pharmacological interventions must be followed before a pharmacological intervention is considered. The quotes below summarise the consensus regarding the appropriate prescription of antipsychotics:

‘I think there is always a place from the spectrum of intervention for these drugs as the last resort in times of distress or, earlier than that, at times of critical need. I think the concern for me is that they may be prescribed as a first resort without consideration.’ (Stokes, 4 February, oral evidence)

‘There is evidence that there are sub-groups of people ...who benefit from these drugs, but I emphasise that it is a sub-group.’ (Anderson, 4 February, oral evidence)

‘Whilst medication is sometimes necessitated, Southern Cross Healthcare advocates that this must be part of a whole care approach and as a very last resort. Antipsychotic drugs should only be given to treat psychotic symptoms and never to manage behaviours that challenge the services.’ (Southern Cross Healthcare)

‘It is important to recognise that this really is a form of restraint – albeit chemical, and its use can only be justified in exceptional circumstances and for the shortest possible time. Patients may become more agitated and aggressive on these drugs rather than less.’ (British Medical Association)

A consultant and senior lecturer in old age psychiatry describes the benefits of prescribing in particular situations in a written submission:

‘I use these medicines often and feel that it is right to be concerned that they are used more than they should. But they are in fact essential in the management of severe distress in people with dementia and without them patients suffer. We have a very few patients whose relatives have refused permission to use them after discussion, and they have sometimes done well without, but at other times the patients have appeared to suffer greatly as a result of this refusal. In the end, in such cases when we have finally agreed treatment, many of them have appeared to settle significantly and to become less distressed and happier.’

53. Making a decision on when a prescription is appropriate depends on several factors, such as the benefits and risks to the individual. The Registered Nursing Home Association summarises this:

‘Drugs are prescribed by individual clinicians for individual patients. They need to base their decisions on the symptoms presenting at the time and on the relative balance of benefit and disadvantage to the individual concerned. They also need to take account of ‘best practice’ guidance pertaining at the time.’

Benefits and risks

54. Evidence from placebo-controlled trials show that these drugs have modest but significant benefits for the treatment of aggression over a 6–12 week period in people with Alzheimer’s disease. The small number of trials for longer than 12 weeks demonstrates that there are no benefits for aggression or other behavioural symptoms over 6–12 months of prescription (Schneider et al 2006).
55. Evidence from these trials also shows that for people with dementia, antipsychotics lead to a number of important and serious adverse events. The side effects of antipsychotics can be very harmful and can rob people with dementia of their quality of life. More recent work has highlighted that there is almost a doubling in the risk of mortality (Food and Drug Administration 2005) and the atypical antipsychotic drugs risperidone and olanzapine increase the risk of stroke by up to three times in people with dementia (Committee on Safety of Medicines, 2004).

56. Often people assume that these side effects are part of the condition and they therefore go unrecognised, when in fact they are a result of the medication. These risks must be given full consideration.

As one witness states:

‘Some of the side effects of neuroleptics lead to more hospital admissions, more GP visits, more casualty visits.’ (Ballard, 5 February, oral evidence)

Many of the submissions from carers show the side effects that antipsychotics can induce:

‘These drugs are lethal. I realised that quite soon, but no one took any notice of what I said. I hold them responsible for his rapid loss of speech, for the constant drooling, his mask-like frozen expression, the constant jerking of his right foot that stayed with him for the rest of his life, and rapid onset of incontinence. Whilst still able to walk he would walk leaning over sideways or backwards at an alarming angle and no doubt it was this ‘unbalancing’ that caused the hip fractures, although no member of staff appears to have seen either of these happen. Soon he developed epileptic fits and although aware that this can be part of Alzheimer’s I cannot be sure that it was not related to the neuroleptics.’

And:

‘All this time he looked anguished and desperately unhappy, his face always contorted, his lips stretched into a sort of snarl, and even in the wheelchair his foot constantly jerking up and down. I got the feeling that these drugs just dampened down his ability to walk and wander, but not the desire to do so.’

And:

‘I am sure that these drugs did affect his quality of life. It is very difficult for nursing homes when someone like my father wanders about a lot. But I believe the constant use of this drug did slow him down considerably and hastened the time he went off his feet.’

NICE-SCIE guideline (2007)

57. Many organisations, for example Age Concern England, point to the NICE-SCIE guideline (2007) as a framework to which health and social care professionals should be working. The guideline sets out how to reach appropriate prescribing decisions as part of its recommendations on the use of pharmacological and non-pharmacological interventions for behaviour that challenges.

58. This guideline clearly shows when prescribing is appropriate and it states that people with Alzheimer's disease, vascular dementia or mixed dementia with severe non-cognitive symptoms may be offered treatment with an antipsychotic drug in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others. They should be a last resort, when all other methods have failed to alleviate distress and/or agitation and only when it is in the best interests of the person.

'The College believes the NICE guidelines provide appropriate guidance as to when the use of antipsychotic drugs are appropriate.' (Royal College of General Practitioners)

'They are evidence based and generally have been very well received by people who practise in that field. They are deemed to be fairly sensible and it does tend to make these distinctions between patient groups who may benefit from one particular approach versus another.' (Anderson, 4 February, oral evidence)

59. However, care homes are carrying out implementation of the guidelines at different levels and it is clear that the existence of good practice guidelines is not in itself sufficient. There are many barriers to implementation as previously discussed in section 2, such as a lack of dementia care training of care home staff, and these must be addressed. There also needs to be monitoring of the extent to which care homes are implementing these guidelines and clear accountability.

Conclusion

60. **The Group concludes that there are some circumstances in which the use of drugs is appropriate. The use of antipsychotics should be a last resort, used at times of severe distress or critical need. The side effects of antipsychotics can be very harmful and can rob people with dementia of their quality of life. The NICE-SCIE guideline (2007) sets out effective and appropriate guidance. However, these are not working in practice and there are barriers to implementation. Steps must be taken to address these.**

How much prescribing is inappropriate?

61. Inappropriate prescribing is clearly a significant problem and the evidence shows that the majority of prescriptions are inappropriate. Witnesses stated:

'If you take all those things into account, my personal clinical experience and research experience in the area would probably suggest that

something like 10 to 30 per cent of prescribing is appropriate and that at least 70 per cent of it probably is not appropriate' (Ballard, 5 February, oral evidence)

Dr Andy Barker's estimate tallied with this:

'The studies I have seen, of either randomised controlled withdrawal of these medications in people with dementia in care homes or indeed some of the small audit studies where pharmacy advisers and GPs have gone in and tried to withdraw medication, the figures I have seen suggest something like half to two-thirds of people on antipsychotics can have those drugs stopped; if they can have them stopped and they can carry on living in the care home then that suggests to me that half to two-thirds of people should not be taking the medication that are taking it. That is the kind of proportion that I would think is inappropriate prescribing, which would tally fairly much with what Clive [Professor Ballard, above] is suggesting.' (Barker, 5 February, oral evidence)

'If you look at a range of published trials in the medical literature it might lead you to suspect that the drugs are prescribed something in the region of twice as often as they need be in terms of benefiting people but this is still a guesstimate.' (Anderson, 4 February, oral evidence)

62. Although there is no direct audit as to what proportion of individuals are prescribed antipsychotics inappropriately, there are some lines of evidence that allow us to begin to answer that question. Evidence on the effectiveness of atypical antipsychotics for people with dementia shows that the use of these drugs is only appropriate in very limited situations. The widespread use of antipsychotics in reality therefore strongly shows that they are being inappropriately prescribed. Prescribing does not always tally with the specific situations described above and with good practice guidelines.

'There are certain justifications and rationales for prescribing medication at certain times, but that does not always follow the rationale, people cannot always give you a rationale as to why that person is prescribed that drug.' (Nightingale, 5 February, oral evidence)

Inappropriate initial prescribing

63. Alzheimer's Society refers to the NICE-SCIE guideline (2007), which state that those with mild to moderate non-cognitive symptoms should not be prescribed antipsychotic drugs. Despite these guidelines, in a recent survey a third of community mental health teams said that antipsychotics were used regularly in their area, even in patients with mild psychotic symptoms (National Audit Office, 2007).

Lack of relationship between symptoms and drugs

64. Further evidence of inappropriateness comes from research by Margallo-Lana et al (2001). They found that there was no relationship between the type of drug used and the type of symptoms for which it was prescribed. Professor Ballard suggests in the oral evidence session (5 February) that this shows either they were either inappropriately prescribed in the first place or that they are not being reviewed and stopped once the symptoms are no longer a problem.

Withdrawal studies

65. The Alzheimer's Research Trust, in their evidence submission, point to their research, which is due to be published soon. Led by Professor Ballard, the research shows that for most patients with Alzheimer's disease, withdrawal of antipsychotics tends to improve functional and cognitive status.

Inappropriate length of time and lack of review

66. The NICE-SCIE guideline states that treatment should be time limited and regularly reviewed (every three months or according to clinical need). This advice is not being followed and research has found that people with dementia are often prescribed an antipsychotic drug for a period of one to two years or longer (Margallo-Lana et al, 2001). This continued prescribing is in the absence of benefit (paragraph 54).
67. Despite being unable to give a precise figure of how many prescriptions are inappropriate, there is strong and widespread concern about inappropriate prescribing. CSCI highlights the importance of this:

'The inappropriate use of antipsychotic drugs, or chemical restraint as it is commonly referred to, is a concern that has been raised in a number of CSCI reports. Rights, risks and restraints (CSCI, 2007) examined people's experiences of the use of restraint in care homes and community settings. We found that 20 per cent of all survey respondents referred to the inappropriate use of medication to sedate or restrain people. While it is important to note that this was not a prevalence study and therefore does not show how widespread the problem is, it does indicate how widespread people's concerns about the problem are.'

Conclusion

68. **The Group is very concerned that the inappropriate prescribing of antipsychotics is widespread. For example, antipsychotics are being used**

for people with dementia who have mild behavioural symptoms and prescribing is often continued for long periods of time in the absence of benefit. This highlights the urgent need to address the barriers preventing the implementation of good practice guidelines and the need for small-scale simple solutions that can be implemented immediately.

4. What can be done to limit the use of antipsychotics?

69. In this section we first explore the possible alternatives to antipsychotics and then we look at the steps that should be taken to ensure the prescription of antipsychotics is limited to instances when it is appropriate and to ensure that care homes can incorporate alternatives into everyday practice.

Alternatives to antipsychotics

70. There are well-documented alternatives to the use of antipsychotics, both small-scale solutions and psychological interventions. Implementing alternatives requires appropriate levels of staff well-trained in dementia care, effective leadership within the home and support from external services. Good practice does exist in some care homes and there needs to be a sharing and widespread implementation of good practice. The Royal College of Psychiatrists agree that what appears clear is that any intervention likely to succeed must be patient-centred, involve training, employ personalised care plans and continuing support for care staff.

Small-scale changes to everyday practice

71. Every care home must implement a person-centred approach to the care of people with dementia. CSCI (in the written evidence) state that:

‘The basis of good care for people with dementia is a person-centred approach where care is tailored and delivered in ways to suit the individual’s wishes, lifestyle, culture and aspirations. This approach must be seen as a priority within care homes and should be led by the manager. Every member of staff should be supported, through appropriate training, skills development and ongoing support and supervision, to work in this way.’

‘It is important that the culture exists in the home that sees the person and their needs right from the start.’ (Fossey, 5 February, oral evidence)

‘I think the key is getting to know the person, starting to understand their history, their hobbies, their interests... By putting other things in place (ie changing design of care home) and trying to understand and by recreating

their jobs, maybe their hobbies, spending time and giving love and friendship we have reduced the use of antipsychotic medication from 80 per cent to 16 per cent.’ (Bryer, 4 February, oral evidence)

72. A person-centred approach requires the development of individually tailored care plans that help carers and staff address behaviour that challenges. The care plan should state the interventions that are appropriate and effective for the individual. In order to have a care plan, people with dementia must have their dementia recognised and diagnosed (paragraph 32).
73. It is also important that a rich and stimulating care home environment is provided. Amanda Thompsell, a consultant old age psychiatrist, provides some good practice examples in her submission, including the promotion of activities in care homes. This reduces boredom and engages service users, which can make substantial differences to their quality of life as well as reducing patterns of behaviour that staff find difficult to cope with.

Psychological interventions for persistent behaviour

74. The NICE-SCIE guideline (2007) recommends a range of non-pharmacological interventions that should be considered before recourse to drug treatment (for example aromatherapy, multi-sensory stimulation, music and dance therapy or massage).
- ‘I think I am persuaded not that the level of evidence is perfect but that what evidence is there is suggesting good benefits and that therefore, given the safety of those approaches, those are a much better first line of approach.’ (Ballard, 5 February, oral evidence)
75. At the moment there is a Cochrane review on psychological therapies being undertaken. This should provide more robust evidence on the use of psychological interventions. As clinicians are already in favour of these interventions, steps should be taken to ensure that they are more widely available and that care staff are able to use them.

Conclusion

76. **The Group concludes that there are more appropriate ways of dealing with challenging behaviour, which some care homes have employed to good effect, and which should be widely used, such as individually tailored care plans and promoting activities within the care home. These need to be put in place across the board and will require the sharing of good practice. This will also require certain steps to be taken to ensure that care homes can incorporate them into everyday practice.**

Staffing levels, training and leadership

77. We will now explore the issue of care staff levels, training and leadership and make recommendations for action.

Dementia care training

78. Many organisations and individual submissions are in agreement that the training of care staff in dementia care is vital. Alzheimer's Society would like to see the development of national standards for dementia care training for care home staff that ensure the workforce is equipped to meet the needs of people with dementia, who make up two-thirds of residents.

79. Training for health and social care professionals working with people with dementia would reduce the number of prescriptions of antipsychotics and support the use of alternative methods for managing behaviour. Research has shown that training and support for care home staff reduces the need to use antipsychotics in residents with dementia and can be a viable alternative for managing challenging behaviour (Fossey et al., 2006).

'These assessments and the administration of any treatment should only be conducted by people with sufficient training and expertise. This points to a fundamental need to improve the training and skill level of health professionals and care home staff and increase access to specialist services.' (Royal College of Psychiatrists)

'If we are questioning the value of neuroleptics, as we are, they (care home staff) have to be skilled to work in a different way, which would be psychological ways, which do involve a shift of thinking, expertise, investment and training if we are going to see the acceptance and maintenance of such training programmes.' (Stokes, 4 February, oral evidence)

80. Training for care home staff should include understanding and implementing person-centred care and how to give every person with dementia the best quality of life. Skills in communication and understanding the benefits and risks of antipsychotic drugs in people with dementia are also essential. Skills for Care has produced a dementia knowledge set. This is a very useful starting point and could be further adapted for use in care homes. Age Concern England also highlight the role of commissioners in securing good quality care through their contracts for services with care homes. Local authorities should also explore how they can use their commissioning power to drive up standards of care home provision in their local area, for example by ensuring staff have the skills to support people with dementia.

Leadership training for care home managers

81. Submissions also highlighted that leadership training is vital for supporting and encouraging care staff managers to provide and promote an environment in the care home that is appropriate for people with dementia. Skills for Care has a workforce development strategy for leadership and management that uses a 'whole system' approach. It provides tools and assistance so that organisations can identify their leadership and management requirements and ensure these are implemented.

Training for general practitioners

82. The British Geriatrics Society states that since the use of antipsychotics depends on the prescriber (which in many cases can be the GP), training for GPs on the management of people with dementia in care homes is needed. The Royal College of Psychiatrists also says that dementia should be included in postgraduate education for GPs and the Royal College of Nursing also calls for increased education on the types of behaviours that will respond to these drugs and the importance of reviewing their efficacy once prescribed. Age Concern England highlight the need for guidance to doctors on the prescription of antipsychotics to people with dementia in the context of the duties of a doctor described in the General Medical Council publication *Good Medical Practice* (2006). As a carer states:

'There is an urgent need for training GPs and hospital-based consultants in the management of these patients, not only in the use of medication, but in all aspects of the condition.'

Staffing levels

83. Strategies must also be put in place to halt the high turnover of staff. Alzheimer's Society report *Home from Home* (2008) makes sensible recommendations for how this might be done. They suggest that training must be:

- Supported by a commitment from government to provide adequate funding, through simple-to-access sources
- Recognised and supported by the regulation and inspection system
- Supported by a career structure and linked to pay
- Supported by a programme of support and effective management to ensure implementation.

'I do not have a high turnover of staff and I think the main reason is that they feel supported and I do recommend training and I will give them

opportunities... I have a care home close to me that pays slightly higher than we do and I am not losing staff; their staff are coming to me.' (Bryer, 4 February, oral evidence)

Recommendation

84. **Dementia training should be mandatory for all care home staff.**
- **Training for care home staff should include understanding and implementing person-centred care, communication skills and the risks and benefits of antipsychotics.**
 - **Training in leadership skills must be available for care home managers.**
 - **More emphasis should be placed on dementia in the training curriculum for GPs. There needs to be improved education for GPs on the behavioural and psychological symptoms of dementia, antipsychotic drugs and alternative solutions.**
 - **Strategies should be put in place to reduce high staff turnover in care homes.**
 - **There is a need to explore how local authorities can use their commissioning power to drive up standards of care home provision in their local area, for example by ensuring staff have the necessary skills to support people with dementia.**

Access to external support services

85. CSCI states that support networks external to the care home are vital, particularly support from local GPs and mental health outreach teams. Care homes must receive effective support from external services, including GPs, community psychiatric nurses, psychologists and psychiatrists, with regular, pro-active visits to the care home. The government must support the development of these specialist services.
86. Ballard et al. (2002) found a psychiatric liaison service significantly reduced the use of antipsychotic drugs, reduced GP contacts and reduced by three times the number of days in psychiatric inpatient facilities.

Recommendation

87. **Care homes must receive effective support from external services, including GPs, community psychiatric nurses, psychologists and psychiatrists, which should involve regular, pro-active visits to the care home.**

The Mental Capacity Act (2005): implementation

88. Many organisations were in agreement that people with dementia, their family and their carers are currently excluded from decision-making regarding the use of antipsychotics. This is despite the fact that the Mental Capacity Act provides an appropriate framework for making decisions and should be used by all organisations working with people with dementia.

‘The rights of people with dementia must be protected and the Mental Capacity Act provides an adequate framework for making a decision in the person’s best interests. It must be ensured that this framework is used to support people with dementia and carers. Therefore Mental Capacity Act training must include issues around restraint and the use of antipsychotics for people with dementia in care homes’. (Alzheimer’s Society).

89. The Relatives and Residents Association clearly states in its submission that the rights of relatives to be informed about what drugs are prescribed and why need to be made more explicit. This means it is vital that care staff, care home residents and their families must be aware of the Mental Capacity Act and what it means.
90. People can refuse any drug treatment as long as they have the capacity to understand the impact of that decision. If someone lacks the capacity to make decisions, then a friend, carer or relative (or advocate) should always be involved as much as possible. The possibility of creating an advanced decision and having an independent advocate must also be made widely known.

‘I advocate to all my care homes that you must involve relatives, you must be involved with relatives, provided the individual wants that – the individual is central to the care. If that individual wants relatives involved, they want to share information, then that should happen. If people are so far along the dementing process that they are no longer able to determine for themselves, they do not have capacity, then again I always encourage relatives to be involved with that; that is something we do encourage within our homes.’ (Nightingale, 5 February, oral evidence)

Recommendation

91. **The use of antipsychotics for people with dementia must be included in Mental Capacity Act training for all care home staff.**
- **The person with dementia and carers must be consulted to ensure that they are fully involved in decision-making when the person with dementia first enters the care home and during their stay.**

- **In order to facilitate the involvement of people with dementia and their carers, information should be provided that meets their needs.**
- **For people with dementia lacking capacity, who have no one else to support them, it must be ensured that an Independent Mental Capacity Advocate is instructed and consulted, as stipulated in the Act.**

Recording and review of medication

92. Tighter mandatory procedures are needed to control the prescribing of antipsychotic drugs to people with dementia and to ensure prompt review and discontinuation.
- ‘I have found that by instituting a simple programme of regular review I have been able to recommend decreases in the prescriptions of antipsychotics for many service users and have been able to take some completely off this medication.’ (Dr Amanda Thompsell, consultant in old age psychiatry)
93. There must be a formal requirement for the prescription decision to be recorded. It must be clear what symptoms a drug is being used to treat (ie why it has been prescribed) in order to effectively review (ie to know whether the drug has been effective or not).
94. There must be a formal requirement for a prescription to be reviewed on a regular basis. Research has shown that a medication review can reduce the amount of medication overall with no detriment to the mental and physical functioning of the patients (Furniss et al., 2000). There is a consensus from the oral and written evidence for this to happen before prescribing and then every three months.
95. Several submissions suggest that regulation in the US is an example of good practice. Evidence from the Nursing Home Reform Amendments in the US shows that prescribing and monitoring regulations can limit the use of antipsychotic. The Nursing Home Reform Amendments (a component of the Omnibus Reconciliation Act 1987, which came into effect in October 1990) were the result of the overuse of antipsychotics in nursing homes.
96. In the US, nursing homes are now required by law to employ a consultant pharmacist to review prescribed medication every one to three months (Furniss, 2002). The Amendments limit the use of antipsychotic medication to specific clinical conditions and demand regular medication review and documentation of decisions. Homes are fined if they fail to adhere to the Amendments.

97. The Residents and Relatives Association suggests that prescriptions of antipsychotics should be time-limited in light of the lack of benefit after 12 weeks. The Royal College of General Practitioners suggest that patients should undergo a trial of decreased medication or have their medication stopped completely if the acute episode has passed, and one witness suggests a three-month break point:

‘Given that the research evidence which Professor Ballard has referred to is saying that actually a 12-week period would be acceptable for a review of risperidone, then it may be that the drugs are reviewed and that there is then a break in prescribing at three months. More often than not people do not then need to take the medication again; very occasionally people may have persistent symptoms which return and it may be then that the drug is prescribed for a short period again and reviewed.’ (Fossey, 5 February, oral evidence)

98. There is a question about who would complete such a review. As one witness said:

‘Although there is lots of national guidance saying these medications must be reviewed three-monthly, none of them say who should do the reviewing. The specialists do not, because they do not have time, the GPs do not because they think the specialists have started them, pharmacy advisers and GPs by and large from my perspective do not stop these medications because they are fearful of the consequences in terms of emerging psychiatric problems again.’ (Barker, 5 February, oral evidence)

99. For Dementia suggests that there is scope for greater involvement from community pharmacists who prepare and dispense the prescriptions to care homes. These pharmacists should have greater responsibility in ensuring prescribing protocols are adhered to and the medication is reviewed regularly. Alzheimer’s Society also makes suggestions as to who should carry out the review:

‘As well as issuing the repeat prescriptions for residents, GPs may themselves carry out detailed medication reviews, and this too has been shown to reduce the prescribing of inappropriate medicines (Khunti and Kinsella 2000). Residents may also benefit from a multi-disciplinary review of their medicines. Indeed, the GPs in one study (Furniss et al 2000) were keen to discuss with the pharmacist the use of medication in residents. However, they often described a lack of time to carry out adequate medication reviews.’

Recommendation

100. **Protocols for the prescribing, monitoring and review of antipsychotic medication for people with dementia must be introduced.**

- **There must be a formal requirement for the prescription to be recorded and then it must be reviewed at a minimum of every three months and more regularly if appropriate.**
- **A prescription should be time-limited because of evidence that the modest benefits of antipsychotics only last for 12 weeks.**
- **A single, named individual must be responsible for undertaking the review and clarity is needed around who this will be.**
- **During the process of prescribing and reviewing antipsychotic drugs, carers or an Independent Mental Capacity Advocate must be consulted.**

Regulation and audit

101. The need for regulation and audit came through very clearly in the oral evidence sessions. Creating audit criteria around the NICE-SCIE guideline (2007), with a particular focus on the prescription of antipsychotic drugs, is strongly suggested by Age Concern England. The Royal College of Psychiatrists suggest that inspection and regulation systems need to be more robust and concern themselves more with day-to-day care of people with dementia:

‘In terms of the audit and monitoring of prescription, now that there are NICE guidelines it should be very possible to create audit criteria that could be tested out and prescriptions could be reviewed according to those criteria. One of the most straightforward things is whether the medication has been reviewed or not, and within the NICE guidelines and in the national service framework it is suggested that treatments should be reviewed every three months, and that accords very well with the evidence base as well, but there is very little evidence that that actually happens in practice. That should be a very straightforward thing to audit.’ (Ballard, 5 February, oral evidence)

102. The Healthcare Commission is commissioning audit standards for dementia care, which, while not produced for care homes, could be developed for care homes. The Care Quality Commission should facilitate inspection incorporating health and social care indices and this should be a priority. The Relatives and Residents Association suggests that the regulatory authority must use sanctions against care homes found to be involved in the misuse of medication.

103. There is an opportunity to influence the new health and social care regulator, the Care Quality Commission:

‘The Government will shortly be consulting on a new set of requirements for the Care Quality Commission to regulate again, and of course things have

moved on in the seven or eight years since those minimum standards were produced so I think it is very likely that that will become an issue in that process of trying to work out what the new regulator should look at, because clearly the numbers and the prevalence of people with dementia has increased quite significantly over that period and, as colleagues have said, is going to become a bigger problem in future than it is now.’ (Walden, 4 February, oral evidence)

‘My interest in having the two Commissions merging is that they should at least have a better chance of having joint priorities, because again I have had frustration in liaising with the Department of Health and having CSCI and the Healthcare Commission say that they were both committed to doing a joint review of older people’s mental health, but when it comes to what has happened to mental health and social care on the ground, when there are cutbacks in finances in particular, then both more or less have separate priorities... but if the Department of Health could get some commitment from the new regulator that they would prioritise this area, and if the dementia strategy highlighted this area as one in particular need of attention, I think that would be very helpful.’ (Barker, 5 February, oral evidence)

104. There is also a need to audit prescribing volumes nationally and locally. This would provide detailed information on the widespread prescription of antipsychotics.
105. A NICE appraisal of antipsychotic drugs for people with dementia is currently outside their remit because the drugs are prescribed off-licence and the paradox that prevents this appraisal must be addressed. This would fit with the recent Health Select Committee (2008) report resulting from the inquiry into the National Institute for Health and Clinical Excellence, which recommended that more appraisals should be aimed at stopping the use of cost ineffective medications.

Recommendation

106. **There should be compulsory regulation and audit.**
- **Creating audit criteria around the NICE-SCIE guideline is strongly suggested and the Care Quality Commission should facilitate this.**
 - **A national and local audit of the prescription of antipsychotics is required and clarity is needed around who would be best placed to complete this.**
 - **There must be a NICE appraisal on the cost-effectiveness of prescribing antipsychotic drugs for people with dementia.**

5. Conclusions and recommendations

The ten conclusions below, drawn from the findings in this report, inform the recommendations that follow.

Conclusions

1. The Group concludes that there is a consensus among patient and professional organisations, the regulators and the care home sector that over-prescribing is clearly a significant problem. We note that evidence of good practice in some care homes is also available (paragraph 15).
2. In our view the evidence builds a picture of behavioural symptoms, experienced as a result not only of the condition, but also as a result of a wider and more complex set of problems external to the individual's condition. Antipsychotics are prescribed, often as a first resort, as a quick and accessible way of managing these behavioural symptoms, such as aggression, shouting and restlessness (paragraph 18).
3. The Group agrees with submissions highlighting that it is important not to trivialise the challenging behaviour shown by people with dementia in care homes, such as aggression, which can have serious consequences. However, antipsychotics can also be prescribed for behaviour that is not causing such extreme distress or risk, such as restlessness or being vocal. (paragraph 23).
4. The Group concludes that the behavioural and psychological symptoms of dementia can be an expression of need. There is a concern that care homes resort to the use of antipsychotics as a solution to this behaviour, when in fact these symptoms are caused by unmet needs that require different solutions, such as a person-centred approach to care or a rich care home environment that provides activities and opportunities for social interaction (paragraph 28).
5. The Group concludes that a lack of dementia care training for staff, high staff turnover and inadequate leadership in a care home setting can partly explain the use of antipsychotics. With little time or training to implement appropriate alternatives, care homes may look to a 'quick' and more accessible method of managing behaviour (paragraph 37).

6. The Group concludes that if care homes had better support from external services this would improve the quality of care provided in the care home. The use of antipsychotic drugs would be reduced by cutting down on the number of new prescriptions and ensuring the appropriate discontinuation of current prescriptions through adequate monitoring and review (paragraph 43).
7. The Group concludes that people with dementia and carers are being excluded from decision-making, despite this being a key requirement of the Mental Capacity Act. This allows care homes and external services in some instances to prescribe without having to fully assess and discuss the situation, such as the risks and benefits of the drugs (paragraph 50).
8. The Group concludes that there are some circumstances in which the use of drugs is appropriate. The use of antipsychotics should be a last resort, used at times of severe distress or critical need. The side effects of antipsychotics can be very harmful and can rob people with dementia of their quality of life. The NICE-SCIE guideline (2007) sets out effective and appropriate guidance. However, these are not working in practice and there are barriers to implementation. Steps must be taken to address these (paragraph 60).
9. The Group is very concerned that the inappropriate prescribing of antipsychotics is widespread. For example, antipsychotics are being used for people with dementia who have mild behavioural symptoms and prescribing is often continued for long periods of time in the absence of benefit. This highlights the urgent need to address the barriers preventing the implementation of good practice guidelines and the need for small-scale simple solutions that can be implemented immediately (paragraph 68).
10. The Group concludes that there are more appropriate ways of dealing with challenging behaviour, which some care homes have employed to good effect, and which should be widely used, such as individually tailored care plans and the promotion of activities within the care home. These need to be put in place across the board and will require the sharing of good practice. This will also require certain steps to be taken to ensure that care homes can incorporate them into everyday practice (paragraph 76).

Recommendations

There are steps that can be taken to ensure the appropriate prescription of antipsychotic drugs to people with dementia in care homes. Steps need to be taken to understand a person's behaviour and alternatives to drugs must be available and implemented.

Overall recommendation: The National Dementia Strategy for England (NDS) must include an action plan to reduce the number of prescriptions.

- 1. Dementia training should be mandatory for all care home staff (paragraph 84).**
 - Training for care home staff should include understanding and implementing person-centred care, communication skills and the risks and benefits of antipsychotics.
 - Training in leadership skills must be available for care home managers.
 - More emphasis should be placed on dementia in the training curriculum for GPs. There needs to be improved education for GPs on the behavioural and psychological symptoms of dementia, antipsychotic drugs and alternative solutions.
 - Strategies should be put in place to reduce high staff turnover in care homes.
 - There is a need to explore how local authorities can use their commissioning power to drive up standards of care home provision in their local area, for example by ensuring staff have the necessary skills to support people with dementia.
- 2. Care homes must receive effective support from external services, including GPs, community psychiatric nurses, psychologists and psychiatrists, which should involve regular, pro-active visits to the care home (paragraph 87).**
- 3. The use of antipsychotics for people with dementia must be included in Mental Capacity Act training for all care home staff (paragraph 91).**
 - The person with dementia and carers must be consulted to ensure that they are fully involved in decision-making when the person with dementia first enters the care home and during their stay.
 - In order to facilitate the involvement of people with dementia and their carers, information should be provided that meets their needs.
 - For people with dementia lacking capacity, who have no one else to support them, it must be ensured that an Independent Mental Capacity Advocate is instructed and consulted, as stipulated in the Act.
- 4. Protocols for the prescribing, monitoring and review of antipsychotic medication for people with dementia must be introduced (paragraph 100).**

- There must be a formal requirement for the prescription to be recorded and then it must be reviewed at a minimum of every three months and more regularly if appropriate.
 - A prescription should be time-limited because of evidence that the modest benefits of antipsychotics only last for 12 weeks.
 - A single, named individual should have responsibility for undertaking the review and clarity is needed around who this will be.
 - During the process of prescribing and reviewing antipsychotic drugs, family members, friends or an Independent Mental Capacity Advocate must be consulted.
- 5. There should be compulsory regulation and audit of antipsychotic drugs for people with dementia (paragraph 106).**
- Creating audit criteria around the NICE-SCIE guidelines is strongly suggested and the Care Quality Commission should facilitate this.
 - A national and local audit of the prescription of antipsychotics is required and clarity is needed around who would be best placed to complete this.
 - There must be a NICE appraisal on the cost-effectiveness of prescribing antipsychotic drugs for people with dementia.

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