Agenda – Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Lleoliad:	I gael rhagor o wybodaeth cysylltwch a:
Ystafell Bwyllgora 1 – y Senedd	**Claire Morris**
Dyddiad: Dydd Iau, 5 Hydref 2017	Clerc y Pwyllgor
Rhag-gyfarfod Aelodau: 09.15	0300 200 6291
Amser: 09.30	SeneddIechyd@cynulliad.cymru

Rhag-gyfarfod anffurfiol (09.15 – 09.30)

1 Cyflwyniad, ymddiheuriadau, dirprwyon a datgan buddiannau

2 Defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – sesiwn dystiolaeth 4 – Ymddiriedolaeth GIG Iechyd Cyhoeddus Cymru

(09.30 – 10.15) (Tudalennau 1 – 32)

Michaela Morris, Rheolwr Gwella Gwasanaethau Iechyd Meddwl, Iechyd Cyhoeddus Cymru

Rhiannon Davies

Egwyl (10.15 – 10.20)

3 Defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – sesiwn dystiolaeth 5 – Coleg Brenhinol y Seiciatryddion a Choleg Brenhinol yr Ymarferwyr Cyffredinol

(10.20 – 11.05) (Tudalennau 33 – 39)

Dr Victor Aziz, Coleg Brenhinol y Seiciatryddion

Dr Jane Fenton-May, Coleg Brenhinol yr Ymarferwyr Cyffredinol

Egwyl (11.05 – 11.15)

4 Defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – sesiwn dystiolaeth 6 – y Coleg Nyrsio Brenhinol

(11.15 – 11.45) (Tudalennau 40 – 41)

Alison Davies, Cyfarwyddwr Cyswllt Ymarfer Proffesiynol, Coleg Nyrsio Brenhinol Cymru

Helen Bennett, Nyrs Iechyd Meddwl ac Ymgynghorydd Iechyd Meddwl, Coleg Nyrsio Brenhinol Cymru

Egwyl (11.45 – 11.50)

5 Defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – sesiwn dystiolaeth 7 – y Gymdeithas Fferyllol Frenhinol a Fferylliaeth Gymunedol Cymru

(11.50 – 12.35) (Tudalennau 42 – 51)

Mair Davies, Cyfarwyddwr, Cymdeithas Fferyllol Frenhinol Cymru

Wendy Davies, Fferyllydd Bwrdd Clinigol Iechyd Meddwl, Cymdeithas Fferyllol Frenhinol Cymru

Steve Simmonds, Fferylliaeth Gymunedol Cymru

Sam Fisher, Fferylliaeth Gymunedol Cymru

Cinio (12.35 – 13.15)

6 Defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – sesiwn dystiolaeth 8 – Cymdeithas Seicolegol Prydain

(13.15 – 13.45) (Tudalennau 52 – 92)

Dr Ian James, Cymdeithas Seicolegol Prydain

Dr Carolien Lamers, Cymdeithas Seicolegol Prydain

7 Papurau i'w nodi

7.1 **Ymchwiliad ar y defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – nodyn ar y sesiwn a gynhaliwyd ar 21 Medi 2017**

(Tudalennau 93 - 94)

8 Cynnig o dan Reol Sefydlog 17.42 i benderfynu gwahardd y cyhoedd o weddill y cyfarfod

9 Defnydd o feddyginiaeth wrthseicotig mewn cartrefi gofal – trafod y dystiolaeth

(13.45 - 14.00)

10 Ymchwiliad i unigrwydd ac unigedd – trafod yr adroddiad drafft

(14.00 - 15.00) (Tudalennau 95 - 132)

Mae cyfyngiadau ar y ddogfen hon

	The Welsh NHS Confederation response to the inquiry into the use of anti-psychotic medication in care homes.
Contact:	Callum Hughes, Policy and Research Officer, Welsh NHS Confederation. [redacted] Tel: [redacted]
Date created:	April 2017

Introduction

1. The Welsh NHS Confederation welcomes this opportunity to respond to the Health, Social Care and Sport inquiry into the use of anti-psychotic medication in care homes.

2. The Welsh NHS Confederation represents the seven Local Health Boards and three NHS Trusts in Wales. We support our members to improve health and well-being by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.

Overview

3. Anti-psychotics are a group of medications usually used in the treatment of mental health conditions such as schizophrenia. They are sometimes inappropriately prescribed to control the behavioural and psychological symptoms of dementia, where their use is commonly associated with a significantly increased risk of harm. Reducing the number of people with a dementia diagnosis inappropriately receiving such medication in care homes has been identified as a key action in the Welsh Government's Draft Dementia strategy.

4. To deliver on such a commitment, work must be done to ensure the effective provision of multi-disciplinary teams within care homes. This means ensuring the provision of effective integration frameworks between neighbouring Local Health Boards and Local Authorities, and also between Local Health Boards and individual care homes. There is also a need to reshape our relationship with dementia patients so that we treat them as partners in these changes and utilise the insights gained through direct experience of living with dementia to further our understanding of the condition and the role played by anti-psychotics within this process.

5. An ageing population and an increasing number of people with multiple long term conditions has meant that utilising medication has become a way of managing often complex behavioural and psychological issues. Where dementia is concerned, it is estimated that between 40,000 - 50,000 people in Wales are currently living with the condition[i]. Against this background, we welcome the Health, Social Care and Sport Committee's interest in this area.

6. Our response will address the terms of reference to the inquiry in turn.

The availability of data on the prescribing of anti-psychotics in care homes, to understand prevalence and patterns of use;

7. The lack of a central point of data makes it difficult to benchmark the level of anti-psychotic prescribing at a care home level as such data is linked back to the prescribing GP, of which there may be many covering one care home. This makes it difficult to identify patterns of use.

8. As such, the only data available to our members in relation to the use of anti-psychotic medication across the relevant Local Health Board would be available only as a result of a manual audit of GP records or an analysis of individual care home prescribing records. However, this can be more difficult for Health Boards with large population bases.

9. Numerous audits have been carried out by Local Health Boards and are ongoing. One of the key findings has been that the use of anti-psychotics is best undertaken during a holistic patient review, including the patient's need for an anti-psychotic by the GP or pharmacist during the regular polypharmacy medication review, rather than being reviewed in isolation.

Prescribing practices, including implementation of clinical guidance and medication reviews;

10. The use of pharmacological interventions to treat the behavioural and psychological symptoms of dementia should only be used when patients are severely distressed, or there is an immediate risk of harm to self or others. The cerebrovascular risk of anti-psychotics needs to be discussed, and target symptoms should be identified quickly so that changes to a patient's medication can be made. Furthermore, the decision to use anti-psychotics should be made only after an individual risk-benefit analysis and monitored closely, with reviews every three months at least.

11. However, it must also be remembered that, while in some cases the clinical view is that medication to relieve severe anxiety may be in a person's best interest, this must be part of a regularly reviewed care plan and not simply considered a convenient and accessible method of subsiding challenging behaviour as and when it arises. These prescribing practices are in accordance with the NICE-SCIE guideline on supporting people with dementia and their carers in health and social care settings.

12. Clinicians within Local Health Boards are broadly aware of such guidelines, but there can be resistance from care homes to reducing or stopping the use of anti-psychotics for fear of relapse. It is encouraging however that our members have reported a number of cases where patients who previously resisted reducing or stopping their anti-psychotic medication have done so in a safe and controlled manner following a discussion with a Nurse Prescriber. Referrals and admissions have reduced significantly the use of anti-psychotic medication in these cases. However, it could be argued that routine prescribing reviews are not the most effective use of a Consultant Psychiatrist's time. An alternative would be for a non-medical prescriber, or an in-reach nurse, to undertake these reviews with an emphasis on educating staff members around medication reduction and support for care homes, thus allowing more time to be freed up for more urgent reviews.

13. It is encouraging also that there have been examples of our members setting up polypharmacy medication pro-forma/review sheets which can be modified by individual practices. These documents will allow care home workers to monitor patient progress and record recommendations for change for patients taking in excess of four different types of medicine. Moreover, reviews have been carried out by specialised teams focusing on the prescription of anti-psychotic medication for elderly people in accordance with NICE guidelines, the Medicines

and Healthcare Products Regulatory Agency (MHRA) recommendations and Local Health Board guidance.

The provision of alternative (non-pharmacological) treatment options;

14. Strategies designed to manage behaviours that often lead to the prescription of anti-psychotic medication services need to be implemented as a whole system approach. This process starts with ensuring the provision of less restrictive and safe therapeutic environments in line with prudent healthcare principles, examples of which may include pleasant outside space or quiet rooms.

15. However, for some care homes and cognitive stimulation groups, it is significantly more challenging to adopt such measures due to an insufficient number of permanent staff members currently employed in local care homes. Reduced occupational therapy resources often mean that opportunities for alternative treatments become even more challenging, despite the fact that our members have made it clear that such functions could be delivered and promoted more effectively by an in-reach worker.

Training for health and care staff to support the provision of person-centred care for care home residents living with dementia;

16. It is encouraging that inpatient dementia wards, in some areas, have activity co-ordinators whose responsibility it is to personalise therapy and patient activities to reduce stress and agitation. It is also encouraging that similar teams have been set up to offer a practical, hands-on approach to integrating non-pharmacological approaches in addressing behavioural challenges for patients living with dementia. Such teams have offered advice and consultation to care home staff to emphasise the importance of exploring alternative treatments in accordance with NICE guidelines.

17. A considerable proportion of training for health and care staff to support the provision of care for residents living with dementia is now done online. It is encouraging that such online resources have incorporated pre-existing materials from the relevant Local Authority and third sector partners, thus developing the integration agenda. There are also a number of projects currently ongoing between GP practices and care homes with a view to identifying residents who show early signs of dementia and the various ways in which carers can respond to their condition. Alternative ways of working have developed in other areas, such as the introduction of a dementia checklist for managing the behavioural and psychological symptoms associated with dementia, and there are a number of good examples of such specialist care being delivered within care homes.

18. However, while it is encouraging to see e-learning on such a scale, a lack of capacity in some areas has meant that it is difficult to provide specialist teaching for staff members to support the provision of care for patients living with dementia. Moreover, while it is undisputed that there are a number of effective initiatives ongoing, there remains considerable space for sharing good practice and training. In particular, there is a great opportunity for Local Authorities and care homes to closer align their ways of working to develop enhanced care settings. This would also be improved by an in-reach role where the training procedures could be repeated, relationships with homes improved and focused on the reduction in the prescribing of anti-psychotic medication.

Identifying best practice, and the effectiveness of initiatives introduced so far to reduce inappropriate prescribing of anti-psychotics;

19. A number of reviews have taken place across Wales in recent years aimed at reducing the prescription of anti-psychotic medication. The results are, broadly speaking, encouraging, though significant challenges around workforce capacity and the sustainability of such measures remain.

20. One of our members in particular is currently piloting the adoption of a new strategy aimed at improving communication on discharge from hospital and ensuring that an indication and a review date is included on any transfer of care documentation to be handed to the patient. This strategy has been brought about following a previous ambitious effort to enhance collaborative ways of working between GPs, pharmacists, care homes, nurses and consultants – while the model was successful in bringing about a reduction in the prescribing of anti-psychotic medication, it was not sustainable and was subsequently discontinued. It is promising however that the Local Health Board in this instance has agreed that an indication and review date will be added to every anti-psychotic prescription for challenging behaviour in dementia.

21. It is encouraging also that a number of Local Health Boards have recently undertaken medication reviews in care homes when requested. These practices have proven particularly effective for patients immediately after their hospital discharge or upon the request of a nurse assessor visiting a particular care home. Reviews are conducted in the care home and in front of the patients themselves, thus involving them as much as possible in their own care and with access to the GP record so that changes in a patient's medication can be quickly reconciled and implemented. Additionally, primary care cluster/local pharmacist roles have been developed as extra clinical pharmacist support which has brought about a greater focus on care home medication reviews. Polypharmacy toolkits such as NOTEARS and STOPP START have been developed and utilised to support medicine optimisation in the medication review process too.

The use of anti-psychotic medication for people with dementia in other types of care settings;

22. It is important to note at the outset that the emphasis on the need to avoid hospital admission means that the likelihood of an individual being prescribed anti-psychotics to keep them at a care home invariably increases. It follows therefore that training for care agencies could be improved to enable home carers to be better able to manage the behavioural problems associated with patients living with dementia without asking for medication.

23. Two Local Health Boards have distributed information leaflets to carers with a view to raising awareness of the risks and benefits of using anti-psychotic medication for patients living with dementia. Both have been recognised as best practice and consideration will be made for ways of monitoring service user feedback. Also, mental health liaison practitioners have been made available in some Local Health Boards to improve the management of dementia patients on non-mental health wards.

Conclusion

24. It is positive to see that a range of approaches are being taken to address the ineffective use of anti-psychotic medication in care homes across Wales. It is suggested that frameworks be established to allow for improved communication and the co-ordination of best practice and learning between Local Health Boards and between care homes to maximise learning

opportunities. This will enable consistent and standardised practices. It is suggested also that this work be undertaken in conjunction with dementia care mapping to identify and gather examples of good practice and wellbeing.

[i] Welsh Government/ Statics for Wales, October 2016. General Medical Services contract: Quality and Outcomes Framework statistics for Wales, 2015-16.

Royal College of Psychiatrists in Wales

Consultation Response

DATE: **21 April 2017**

RESPONSE OF: **THE ROYAL COLLEGE OF PSYCHIATRISTS in WALES**

RESPONSE TO: **National Assembly for Wales Health, Sport and Social Care Committee – Inquiry into Antipsychotic Medication Prescribing Practices in Care Homes**

The Royal College of Psychiatrists is the professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and in setting and raising standards of psychiatry in the United Kingdom.

The College aims to improve the outcomes of people with mental illness, and the mental health of individuals, their families and communities. In order to achieve this, the College sets standards and promotes excellence in psychiatry; leads, represents and supports psychiatrists; improves the scientific understanding of mental illness; works with and advocates for patients, carers and their organisations. Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies.

RCPsych in Wales is a satellite of the Central College, representing over 550 Consultant and Trainee Psychiatrists working in Wales.

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The RCPsych in Wales is pleased that the Committee is seeking views on the use of antipsychotic medication in care homes. This is an area of concern for the College in Wales and we have, over many years, been aware of issues of over prescribing and inappropriate use of antipsychotic medication in the elderly population.

This response has been produced in consultation with the members of the College in Wales and relevant stakeholders.

The RCPsych in Wales has previously published a briefing paper on prescribing practices in the elderly:

- Briefing paper on Over prescribing in the Elderly

RCPsych in Wales Key recommendations:

1. **A cycle of Local and Nationals audit into Antipsychotic prescribing practices in Wales**
   The Faculty of Old Age Psychiatry and the RCPsych in Wales is calling for a Wales-wide cycle of audits to gather data on anti-psychotic prescribing practices. The availability of hard data on prescribing practices is critical to understand prevalence and patterns of use.

   We would recommend that the audits also gather evidence on whether the patient received anti-psychotic medication as first option treatment, and/or whether there were alternative therapies available within their locality. This will provide the ability to assess whether the use of anti-psychotic medication is affected where alternative methods of treatments are available.

2. **Routine use of STOPP/START. Screening tool of Older Persons' potentially inappropriate prescriptions (STOPP)/Screening tool to Alert doctors to the Right Treatment (START) tool (Gallagher et al, 2008).**
   Demographic changes mean that prescribing for older people is an increasingly important aspect of daily clinical care. Older people have a high prevalence of chronic and multiple illnesses and are likely to be prescribed multiple medications. Pharmacokinetics and pharmacodynamics may be altered by ageing or disease. This puts elderly people at a high risk of adverse drug reactions (ADRs), adverse drug events (ADEs) and drug-drug interactions. They may also be exposed to medication errors or potentially inappropriate prescribing (PIP) with significant clinical and economic impact. The STOPP/START tool[1] has been developed to identify older people at risk from adverse drug effects and to reduce the risk of initiating drugs likely to cause adverse events. The tool comprises 65 clinically significant criteria for potentially inappropriate prescribing in older people.

[1] https://www.rcpsych.ac.uk/pdf/Aziz%20Stopp-START%20tool%20paper%20-%20Victor%20Aziz.pdf

- Antipsychotic medicines should not be routinely prescribed to treat behavioural and psychological symptoms of dementia.
- In line with NICE guidance, when an antipsychotic medicine is required, the lowest dose should be prescribed for the shortest time with regular review by an appropriately skilled pharmacist as part of the multidisciplinary team.
- Pharmacists who deliver enhanced support for care homes should be able to access quality continual professional development opportunities in relation to antipsychotic prescribing.

The Royal College of Psychiatrists in Wales recognises that there is a need to prescribe antipsychotic medication on occasion to treat severe behavioural and psychological symptoms in dementia. However, such medication should be reviewed and reduced as soon as it is practical and *safe* for the patient and those treating the patient. Other treatment options should be considered at the earliest opportunity.

3. **Medication reviews upon admission to Care Home settings and regular ongoing medication reviews for all residents.**

   In line with recommendations from The Royal Pharmaceutical Society (Wales) report 'Improving Medicines Use in Care Homes (2016)' [2]
   - As part of a multidisciplinary review, all residents should receive a review of their medication by a pharmacist when they first move into a care home in order to optimise their medication regimen.
   - Residents should receive a minimum of one annual medication review from a pharmacist with additional support for significant medication changes. For patients with complex medication regimens, this review should increase to every 3-6 months.
   - With patient consent, all pharmacists directly involved in patient care should have full read and write access to the patient's health record in the interest of high quality, safe and effective patient care.

The RCPsych in Wales recommends that 'discharge from hospital reviews' should routinely take place. We are aware of some work within Welsh Government to develop the required IT infrastructure to enable this and welcome this development.

The RCPsych in Wales recommends that *all* necessary antipsychotic prescribing is supported by a risk/benefit analysis for each patient performed by an appropriately trained specialist as part of the multi-disciplinary team.

We further recommend the involvement of community pharmacists, GPs, family and patients in medication reviews. Community pharmacists should be dealing specifically with care home residents, and would be able to make recommendations to the prescribing medic/MDT.

4. **Adequate training in medication for carers and staff**

The RCPsych in Wales recommends that *all* carers and staff have training to develop an understanding of possible side effects of antipsychotic medications prescribed within care home settings. This will enable carers and staff at *all* career grades to raise concerns

[2] https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Publications/Improving%20medicines%20use%20for%20care%20home%20residents.pdf

where an adverse reaction is suspected in order to enable senior staff to conduct a medication review quickly and effectively.

The RCPsych in Wales is encouraged by the introduction of the Care and Social Services Inspectorate Wales' Care Home Training Guides[3]

We would also recommend informed consent in patients with mild to moderate cognitive impairment, that the effect of prescribed medication, both positive and negative, is explained as fully as possible. To enable this, speech and language therapists have a role in training health and voluntary sector staff, including care home workers in identifying communication difficulties in dementia and strategies to support and enhance communication.

5. **Access to non- pharmacological therapies and treatments**

It is increasingly recognised that pharmacological treatments for dementia should be used as a second-line approach and that non-pharmacological options should, in best practice, be pursued first[4]. The more traditional treatments such as behavioural therapy, reality orientation and validation therapy, and newer treatments such as cognitive therapy, aromatherapy and multisensory therapies all have therapeutic benefit to patients with dementia.

Speech and Language Therapists (SLTs) have specialist knowledge to directly assess the connection between unmet communication needs and challenging behaviour, and provide advice on maximising communication function to the care home resident, their family and carers.

Example of good practice

Cwm Taf Health Board – Care Home Dementia Intervention Team

Cwm Taf University Health Board is improving the quality of like for care home residents with dementia. The Care Home Dementia Intervention Team is the first of its kind in Wales and provides an alternative to medication for behaviour that challenges.

The service explores the possible reasons why a person is distressed of behaving in a challenging way. This enables the service to work with care home staff to develop a person-centered care plan.

A successful pilot was held in Ty Eiren, a care home in Tonyrefail, where person-centered care plans were developed for residents with dementia and challenging behaviour. The plans included a variety of interventions such as reminiscence, music therapy, life story work and doll therapy.

Fiona Senior, Clinical Psychologist said 'To offer a service without medication is amazing'.[5]

[3] http://cssiw.org.uk/news/item?lang=en
[4] http://apt.rcpsych.org/content/10/3/171
[5] http://cwmtaf.wales/innovative-teamwork-cwm-taf-enables-care-home-residents-live-well-dementia/

Advice on conducting medication reviews in care homes with the aim of improving quality of life for residents

As hospital doctors become increasingly sub-specialised, GPs are absolutely critical to ensuring that medications prescribed by individual specialties are appropriate for that person.

This is based on an extensive knowledge of the patient, knowledge of the drug, access to the complete medical record and the shared approach to prescribing that is often applied.

GPs are regularly involved with medication reviews and their approach to medication reviews will vary from practice to practice.

Medication reviews undoubtedly improve quality of life for care home residents and the process can also improve relations between clinicians, staff, patients and relatives.

It should be noted that there can also be significant cost savings due to reduced prescriptions.

Pharmacists can be key in setting up medication review systems with the ability to identify a significant number of inappropriate prescriptions over time. They can provide the necessary link between clinicians and staff to realise the importance of this work as well as engaging patients and their relatives. The pharmacist can also ensure that any interventions taking place are appropriately reviewed.

From the evidence available, it is clear that there are risks associated with the use of antipsychotic medication, particularly for people with dementia in care home settings. Antipsychotics appear to be used all too often as a formulaic first-line response to any behavioural difficulty in dementia rather than as a considered second-line treatment when other approaches have failed. Data suggests that antipsychotics are used too often in dementia. The high level of initiation and maintenance of these medications in this vulnerable group means that any potential benefit of their use in specific cases is likely to be outweighed by the serious adverse effects of their use in general. In order to generate a plan that will work we need to understand the determinants of this behaviour and the reasons for its persistence.[6]

The Royal College in Wales welcomes the opportunity to input into work on this issue over the coming months.

Dr Victor Aziz

Chair, Faculty of Old Age Psychiatry, RCPsych in Wales

[6] https://www.rcpsych.ac.uk/pdf/Antipsychotic%20Bannerjee%20Report.pdf

RCGP Wales response on use of anti-psychotic medication in care homes

RCGP Wales welcomes the opportunity to respond to the Health, Social Care and Sport Committee short inquiry on the use of anti-psychotic medication in care settings, particularly care homes.

Antipsychotics are drugs developed and licensed to manage schizophrenia and their use for this is wide. Typical antipsychotics are associated with common and serious adverse effects, including over-sedation, hypotension, involuntary movements (including irreversible late onset tardive dyskinesia), Parkinsonian symptoms (rigidity, tremor and problems with walking) and the rare occurrence of cardiotoxicity (damage to the heart), high fever and vascular collapse (neuroleptic malignant syndrome). Since their introduction, the use of the atypical antipsychotics has become much more common, due to their generally favourable side effect profile, with the incidence of Parkinsonian side effects and tardive dyskinesia much lower and is to be supported even in care homes. They are also used commonly to manage disturbed behaviour e.g. agitation, aggression, wandering, shouting, repeated questioning and sleep disturbance, in patients with other conditions, particularly dementia or those with learning disability.

Many people in care homes and those with dementia have multiple co-morbidities and the use of any medication with significant side effects needs to be kept to a minimum, both in duration and in dosage. Antipsychotics, particularly the older typical ones have marked side effects as mentioned above. The newer atypical antipsychotics have less incidence movement disorders and are now more commonly used. Traditional clinical trials have only looked at short term usage. There are suggestions that side effects are more frequent with long term usage of antipsychotics and in those who have repeat use, as well as those who have other co-morbidities.

Patients who are suffering from behaviour problems should be fully assessed to determine underlying problems e.g. disturbed sleep pattern, acute illness, pain, which is contributing to the alerted behaviour pattern. This is consistent with NICE guidelines https://www.nice.org.uk/advice/ktt7/chapter/Evidence-context . Should patients be started on antipsychotics they need to be monitored regularly for side effects including cardiac ones using ECGs. Dosages and duration of medication should be kept to a minimum.

Potentially, the development of behaviour problems may be higher in care homes than in patients' own homes, where they are surrounded by familiar objects and people. The monitoring of patients in care homes for side effects should, however, be easier and more frequent than outside this environment.

When patients with dementia or learning disability are admitted to hospital, the change of environment and the underlying condition / reason for admission may exacerbate to precipitate behaviour problems. These patients may be given antipsychotics but notes should clearly indicate that these should be withdrawn following the acute episode and discharge to their normal surrounding.

More support is needed for primary care, such as, access to multidisciplinary team input in managing patients who present with behavioural disturbance and quarterly review with a CPN for those on an anti-psychotics.

GPs are often under pressure from care home staff to use medication to manage disturbed behaviour in patients, who might be better managed by different forms of distraction or stimulation.

There is also pressure on GPs to prescribe antipsychotics from psychiatrists, particularly the elderly. GPs need to be supported by mental health colleagues to follow the good clinical guidelines set out by NICE and reduce the use of antipsychotics for these unlicensed uses of managing behaviour problems.

21 April 2017

Response from the Royal College of Nursing Wales to the Health, Social Care & Sport Committee Committee's Inquiry into the use of anti-psychotic medication in care homes

The Royal College of Nursing is grateful for the opportunity to respond to this inquiry. Whilst the terms of reference ask for consideration of a number of specific areas, our response will focus on a few overarching points.

General comments

I. Medicines management in an environment where people receiving medicines are vulnerable and suffering a range of comorbidities, often with compromised capacity, is complex and multifaceted. The importance of contemporaneous, skilled assessment and care planning cannot be overstated.

II. Care homes must have a written policy and procedure on the administration of medicines, and all staff working in the home should be aware of the policy and should be working to it at all times. Registered nurses must also work to the NMC's Standards for Medicines Management. The vast majority of registered nurses and care home staff adhere to these standards and policies and the care delivered is to a very high standard.

III. The Royal College of Nursing Wales' prestigious Nurse of the Year Awards have frequently acknowledged the excellent work of nurses and healthcare support workers in care home settings and with people with dementia.

Staffing levels and time to care

IV. Providing and managing health services means caring for people. Preventing, assessing, treating or managing an illness means caring. Pain relief and ensuring a patient is nourished and hydrated means caring. Nursing is caring. Caring for someone requires time, time to learn, time to listen and talk, time to assess, time to provide care, delegate or escalate, time to reflect and improve practice. It takes time to care.

V. In 2015 the Royal College of Nursing Wales ran a member survey to find out what issues mattered most to our members. The two issues that came out top for improving patient care were:
- maintaining safe nurse staffing levels
- ensuring that the staff who deliver patient care have the time and training needed to deliver this care with the dignity and respect that patients deserve

VI. This clearly demonstrates the importance of having the right number of staff with the right level of supervision to ensure the best possible care for patients and care home residents. It is important that the team has senior, experienced

and qualified members who can provide supervision and oversight. The team needs to have the time to safely and sensitively care for the patients assigned to it, and members of that team need continuous professional development. It is when these standards are not met that errors in judgement can occur, and standards of care can decline.

VII. Patients with dementia have specific and complex needs, and those with dementia in a care home are likely to require greater levels of care than other patients in similar settings. This should be reflected in the calculation of nurse staffing levels. The Committee may wish to consider whether there is any evidence of a relationship between dubious prescribing practices in care homes, and the ratio of registrants to patients in such settings.

VIII. Care homes should also ensure that they are able to offer a range of treatment options for people with dementia, including evidence based psychological therapies where appropriate.

About the Royal College of Nursing

The RCN is the world's largest professional union of nurses, representing over 430,000 nurses, midwives, health visitors and nursing students, including over 25,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing. The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

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Wales Cymru

Use of anti-psychotic medication in care homes

Response from the Royal Pharmaceutical Society in Wales

About us

The Royal Pharmaceutical Society (RPS) is the professional body for pharmacists in Great Britain. We represent all sectors of pharmacy in Great Britain and we lead and support the development of the pharmacy profession including the advancement of science, practice, education and knowledge in pharmacy. In addition, we promote the profession's policies and views to a range of external stakeholders in a number of different forums.

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Dr Dai Lloyd AM
Chair - Health, Social Care and Sports Committee
National Assembly for Wales
Cardiff Bay
Cardiff,
CF99 1NA

20th of April 2017

Dear Dr Lloyd

RE: Use of anti-psychotic medication in care homes

The Royal Pharmaceutical Society (RPS) Wales welcomes the opportunity to respond to the consultation on the use of anti-psychotic medication in care homes. We are pleased that reducing the inappropriate use of antipsychotic medicines, particularly for individuals living with dementia, is a key priority for the Welsh Government. This is also one of the RPS Wales's key recommendations, set out in our policy *document* *'IMPROVING MEDICINES USE FOR CARE HOME RESIDENTS'.* This document was supported by a number of Royal colleges and Third sector groups and includes a number of recommendations and case studies that may be of interest to the Committee.

Antipsychotic medicines are used for some types of mental distress or disorders. A 2009 report by Professor Sube Banerjee: *The use of antipsychotic medication for people with dementia* '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.' This suggests that of the 180,000 prescriptions for people with dementia, approximately 140,000 were inappropriate. This is around two thirds of overall use of the drugs for people with dementia. It also found that antipsychotic drugs have been used inappropriately in all care settings and specifically references use in care homes.[1] [2]

When an individual with dementia exhibits behaviour that is challenging, we would expect support tools such as the Alzheimer's Society "This is Me" toolkit to be used to

[1] Banerjee, S. 2009. The use of antipsychotic medication for people with dementia: Time for action. The Institute of Psychiatry, King's College London (Commissioned by the Department of Health). Available at: http://www.rcpsych.ac.uk/pdf/Antipsychotic%20Bannerjee%20Report.pdf (Last Accessed: January 19 2016)

[2] Royal Pharmaceutical Society, Wales. 2016. Improving Medicines use for Care Home Residence. Available at https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Publications/Improving%20medicines%20use%20for%20care%20home%20residents.pdf (Last Accessed: April 12th 2017)

ensure a holistic approach to care is taken. Non-pharmacological treatment options should be looked at as a first line approach. Ensuring all individuals have the opportunity to communicate is very important and access to communication support provided by Speech and Language Therapists could be a vital step to ensuring greater person-centred care. We also believe that there needs to be a greater focus on ensuring support measures are put in place to help residents live well, supported by increased levels of training for health and social care staff to provide person-centred care.

Antipsychotic medication should only be used after non-pharmacological methods have been tried and where there is a potential risk to patient and others. When an antipsychotic medicine is required, the lowest dose should be prescribed for the shortest time with regular review by an appropriately skilled pharmacist as part of the multidisciplinary team. We strongly support the good practice for prescribing in older people set out by the Royal College of Psychiatrists in Wales, Old Age Faculty's briefing paper on over prescribing from February 2015. We were very pleased to work in partnership with the Royal college of Psychiatrists on the Antipsychotic medicines information in our policy document 'IMPROVING MEDICINES USE FOR CARE HOME RESIDENTS'.

The pharmacy team; pharmacists and registered pharmacy technicians, have significant expertise to support medicines management and safe administration for all care home residents as part of a multidisciplinary team approach. Regular medicines reviews from a pharmacist should be available to all people with a chronic condition such as dementia, including those living in care homes, to help optimise individual medication regimes and reduce inappropriate use of antipsychotics.

The changing and evolving role of pharmacists offers significant opportunities to improve care in Wales. The development of primary care clusters and greater use of the skills of pharmacist independent prescribers in multidisciplinary teams has the potential to improve the care of care home residents. We believe now is the time to build on the principles of prudent healthcare to fully harness the expertise of the pharmacy profession as a part of the solution to meet the challenges in managing medicines in care homes.

The RPS Wales care home policy document sets out several recommendations under five key themes that will improve the care, safety and quality of medicines use for residents living in care homes. The use of antipsychotic medication is just one important part of this.

The recommendations are:

1. Polypharmacy

1.1 As part of a multidisciplinary review, all residents should receive a review of their medication by a pharmacist when they first move into a care home in order to optimise their medication regimen.

1.2 Residents should receive a minimum of one annual medication review from a pharmacist, with additional support for significant medication changes. For patients with complex medication regimens, this review should increase to every 3-6 months.

1.3 With patient consent, all pharmacists directly involved in patient care should have full read and write access to the patient health record in the interest of high quality, safe and effective patient care.

2. Antipsychotic prescribing

2.1 Antipsychotic medicines should not be routinely prescribed to treat behavioural and psychological symptoms of dementia.

2.2 In line with NICE guidance, when an antipsychotic medicine is required, the lowest dose should be prescribed for the shortest time with regular review by an appropriately skilled pharmacist as part of the multidisciplinary team.

2.3 Pharmacists who deliver enhanced support for care homes should be able to access quality continual professional development opportunities in relation to antipsychotic prescribing.

3. Safe transfer of information

3.1 Reconciliation of medicines should be undertaken by a pharmacist when a person moves to a care home from their own home or another care setting to ensure that their medication is maintained accurately.

4. Education, training and standards

4.1 The development of national standards for medicines training to ensure uniformity across Wales as well as reflecting current practice for care home staff.

4.2 Inspections of care homes should include the expertise of a pharmacist to address medication issues and improve medicines safety.

5. Palliative and end of life care

5.1 A national review of the current provision of palliative and end of life medication to residents as part of steps to develop all Wales standards for anticipatory prescribing in care homes.

5.2 The multidisciplinary care team for a resident needing palliative care support should have access to the expertise of a specialist palliative care pharmacist.

We also strongly support the Faculty of Old Age Psychiatry and the RCPsych in Wales's call for a Wales-wide cycle of audits to gather hard data on anti-psychotic prescribing practices to better understand prevalence and patterns of use.

The use of antipsychotic medication in care homes is an important issue that has been seldom addressed in Wales. We therefore welcome this inquiry and trust this response is helpful. We would also welcome the opportunity to discuss any of the above points in further detail with yourself and other members of the Committee and also to share further examples of good practice that we are aware of.

Yours faithfully

Suzanne Scott-Thomas, Chair, Welsh Pharmacy Board

The Community Pharmacy Wales response to The Health, Social Care and Sport Committee inquiry into

The use of anti-psychotic medication in care homes

Date: April 2017

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Part 1: Introduction

Community Pharmacy Wales (CPW) represents community pharmacy on NHS matters and seeks to ensure that the best possible services, provided by pharmacy contractors in Wales, are available through NHS Wales. It is the body recognised by the Welsh Assembly Government in accordance with *Sections 83 and 85 National Health Service (Wales) Act 2006* as 'representative of persons providing pharmaceutical services'.

CPW represents all 717 community pharmacy contractors in Wales. These include all the major pharmacy multiples as well as independent businesses. Contractors are located in high streets, town centres and villages across Wales as well as in the major metropolitan centres and edge of town retail parks.

CPW is pleased that the Committee is looking at the important issue of the prescribing, management and use of anti-psychotic medication in care homes. Even with the one to one support provided to residents in a care home, the frail elderly remain a vulnerable group of patients. As the demands of an ageing population continue to grow and NHS funding comes under greater pressure the temptation to turn to medication as a cheap and convenient solution to the management of behavioural and psychological issues in people living with dementia, will become even more significant over time.

Part 2: Specific comments relating to the Terms of Reference for the Inquiry

CPW has been asked to submit information relating to the specific terms of reference of the inquiry.

Item 1: The use of anti-psychotic medication in care home settings, and the ways in which its inappropriate use could be reduced.

CPW is concerned that, as the anti-psychotic problem has grown, it has coincided with a decrease in the commissioning of community pharmacy care home support services and a decrease in pharmacist input into the management of medicines in care homes in general.

CPW fully supports the principles contained in *Your Care, Your Medicines* that:

> *"Patients with supported living needs, whether living independently in their own homes or in a care home setting, must benefit from access to the pharmacy team to help manage their medicines effectively and to maintain their health and wellbeing."*

The effective prescribing and use of medicines remains the backbone of modern healthcare and CPW believe that, as pharmacists are the experts in medicines, pharmacists should be involved in all situations where medicines are prescribed, supplied and administered irrespective of the residential status of the patient.

Over a number of years CPW has witnessed the steady decommissioning of *Community Pharmacy Care Home Support Services* and this removal of much needed support has coincided with the Care and Social Services Inspectorate Wales (CSSIW) policy decision to no longer directly employ pharmacists within the team.

Against a background of growing evidence of medication errors in care homes, and inappropriate use of antipsychotic medication, CPW is extremely concerned that at the very time care homes require greater support in managing medicines, the support available to care homes from community pharmacy teams has virtually disappeared.

CPW would ask the Health, Social Care and Sport Committee to review this situation as a matter of urgency and to ensure that all care homes receive regular community pharmacist advice and input into medicines management processes and medicines administration training for their staff..

Item 2: The availability of data on the prescribing of anti-psychotics in care homes, to understand prevalence and patterns of use.

CPW is not aware of the data sources relating to the prescribing and use of anti-psychotics in care homes but suspects that data may not be simple to access. CPW would suggest that care home support services are commissioned from community pharmacy for all care homes and that the CPW template service is amended to include a more detailed review on the use of anti-psychotics and the capture and sharing of relevant data on prescribing and use.

If there is a will in either Welsh Government or its health boards for a specific anti-psychotic medication support service from community pharmacies, CPW is happy to work with partners on the design of the service.

Item 3: Prescribing practices, including implementation of clinical guidance and medication reviews.

All care homes will receive their medication from a community pharmacy of their choice and it is common for the majority of pharmacies supplying care homes to offer some level of medicines management support to care homes. This arrangement however is a private arrangement between the care home and the supplying pharmacy and as a result the nature of the support provided will vary considerably and there is no standardisation of the support provided.

CPW would recommend that, irrespective of the supply arrangements between community pharmacies and care homes, NHS Wales ensures that a more structured and formal community pharmacy care home support service is commissioned from the supplying pharmacy. In this way regular structured visits would take place, the relationship between the care home staff and the pharmacy team would be allowed to develop over time and medicines management and prescribing in areas such as anti-psychotics would be routinely monitored.

Item 4: Provision of alternative (non-pharmacological) treatment options.

There are several types of cognitive therapy that could benefit people with dementia such as cognitive stimulation activities, group-based activities, reminiscence therapy and cognitive rehabilitation. While it is important to explore alternative therapies either as first line treatments or as adjuncts to medication, these services will need to be provided by experts in these services and are outside of the skills and expertise of community pharmacists to provide.

Item 5: Training for health and care staff to support the provision of person-centred care for care home residents living with dementia.

CPW fully recognises that while a structured review of medicines management processes will help to reduce less than optimal care of dementia, the real gains will be made by improving the knowledge and expertise of the health and care staff involved in the management of the patient and the provision of their medication on a daily basis.

Community pharmacy teams were widely involved in the training of health and care staff in medicines administration, however this now happens on an adhoc basis following the decommissioning of the care home service.
It is for this reason that CPW has included the training of health and care staff as one element of their template service.

CPW stands ready to work with health or social care providers to tailor a pharmacy service to meet their specific needs which could well include more focused training on the management of people with dementia.

Item 6: Identifying best practice, and the effectiveness of initiatives introduced so far to reduce inappropriate prescribing of anti-psychotics.

NICE guidelines recommend that the prescribing of anti-psychotic medication should be reviewed every three months. CPW understands that this is not currently the case in the majority of situations. In response, CPW would recommend that a three monthly audit of the use of anti-psychotic medication is undertaken by the supplying community pharmacy as part of the care home support service. This change would ensure that regular reminders are in place when a patient requires a review. In addition data from pharmacy care home visits would then be available to stakeholders on a national basis to support national quality standards.

Item 7: The use of anti-psychotic medication for people with dementia in other types of care settings.

The Discharge Medicines review Service has been amended so that it now covers the discharge to and from any care setting. This change has not been widely recognised and CPW would recommend that a community pharmacy DMR is built into the care pathway for all transfers of care.

The sound medicines management support and person centred care, encompassed in the community pharmacy care home service, can be tailored to meet the needs of any individual care setting as the pharmacists knowledge and skills are transferrable. Pharmacists as the experts in medicines should be the professionals that undertake all medicines management interventions.

Part 3: Conclusion

CPW would recommend that the Health, Social Care and Sport Committee ask the Welsh Government to ensure that arrangements are put in place for all care homes to receive a regular, structured, audit and advice visit, from the community pharmacy that supplies their medication and that a three-monthly audit of anti-psychotic prescribing is part of that review.

CPW agree that the content of this response can be made public.

CPW welcomes communication in either English or Welsh.

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Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-26-17 Papur 7 / Paper 7

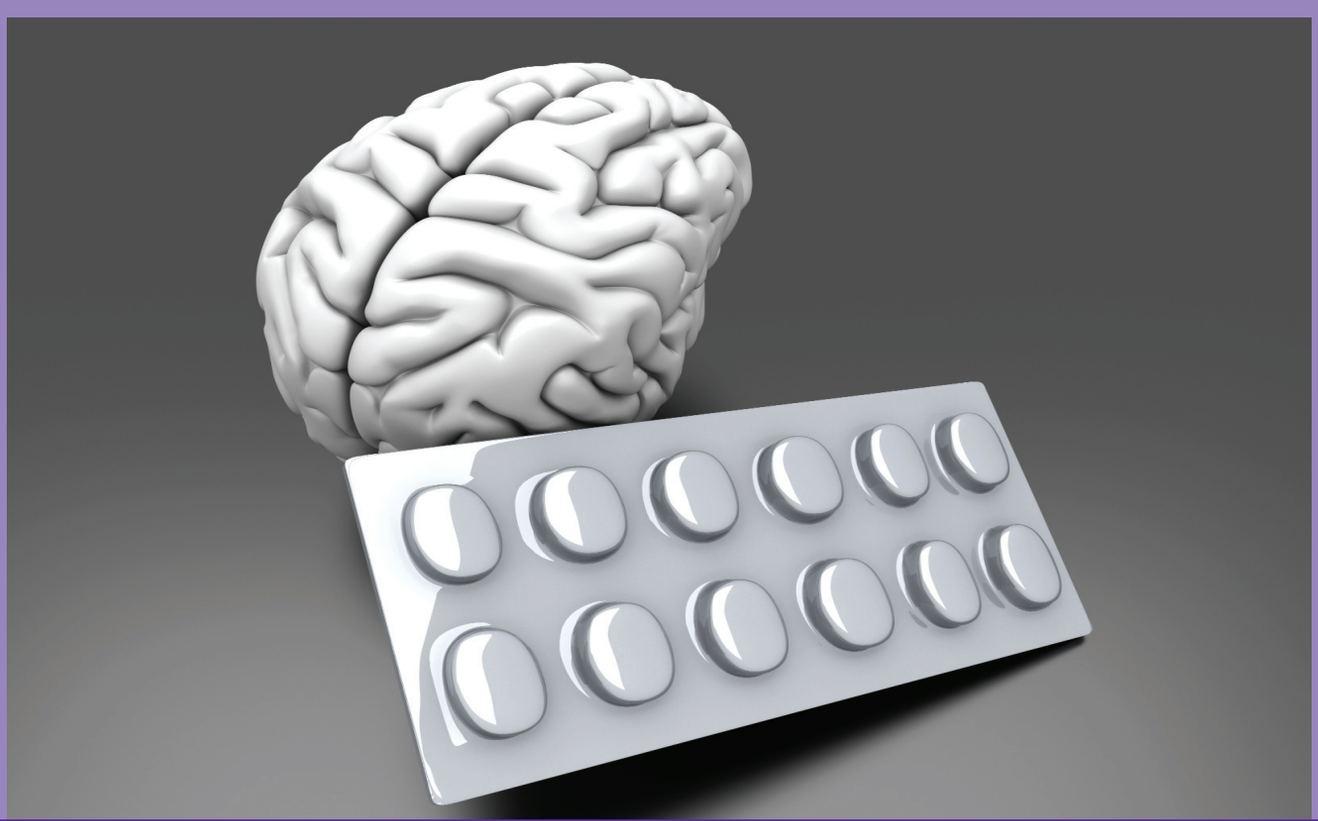
Eitem 6

The British Psychological Society

Division of Clinical Psychology
Faculty of the Psychology of Older People

Briefing paper

Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia



March 2013

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INF 207/2013

Printed and published by the British Psychological Society.

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Incorporated by Royal Charter Registered Charity No 229642

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Executive summary

The Department of Health has stated that the use of antipsychotic medication for people with dementia needs to be reduced in order to limit the risk of harm associated with these medications in this frail and vulnerable group of people. The question is whether there are any alternatives, and whether these can be effective in reducing reliance on antipsychotic medications.

A number of initiatives have developed to support this work, including the Dementia Action Alliance (DAA) 'Call to Action' in June 2011. As one of the partner organisations within DAA, the British Psychological Society committed to reviewing the evidence for evidence-based non-pharmacological alternatives to antipsychotic medication. The present report is the product of this work.

The Faculty of the Psychology of Older People, which is part of the Society's Division of Clinical Psychology, has brought together an expert reference group to review the relevant literature and to lay out the evidence in a clear and accessible manner. The Faculty's work highlights that there are evidence-based alternatives to antipsychotic medication for people with dementia. It also shows that if these are organised in a staged approach (that is, a stepped care approach) then access to these interventions can be increased and the reliance on antipsychotics should be reduced. Therefore, the model is presented to assist commissioners and providers of care when considering how to care for people with dementia, particularly when their well-being is compromised and/or when there are difficulties in managing aspects of the person's behaviour.

This document is intended for use across the UK as a whole. There are, however, areas in which different policy and guidance are relevant for different nations. Nevertheless it is hoped that as this document is addressing assessment and interventions, that it will be transferable across the home nations. Each of the home nations is aware of the rising numbers of people with dementia. They are committed to providing a framework for services to operate within to address this rise by improving the lives and services for people with dementia (Department of Health, 2009; Department of Health, Social Services and Public Safety in Northern Ireland, 2011; Scottish Government, 2010; NHS Wales 2011).

Dr Donald Brechin
Past Chair of the Faculty of the Psychology of Older People
On behalf of the Working Group

Introduction

There are approximately 800,000 people currently living with dementia in the UK with approximately a third of this number residing in a care home (Alzheimer's Society, 2011). It has been predicted that by 2021 there will be over one million people living with dementia. The financial cost is expected to grow from an estimated £20 billion in 2010 to over £27 billion by 2018 (All-Party Parliamentary Group on Dementia, 2011).

The majority of people living with dementia are likely to experience the development of behavioral and psychological difficulties at some point during their illness. It has been suggested that these behaviours may be present in up to 90 per cent of people living with Alzheimer's disease (Robert et al., 2005). Such behaviour includes occurrences of hitting, kicking, nipping, screaming, apathy, pacing, non-compliance, urinating in inappropriate places and disinhibition (James, 2011) as well as confusion, calling out, repetitive questioning, toileting difficulties, misidentifications and sexual challenge (Stokes, 2000).

A variety of terms are used to describe the phenomenology of where the person with dementia engages in behaviour that challenges others and/or reflects a level of apparent distress for the person with dementia. As such, a number of terms may be used to refer to these presentations within this document. The terms 'challenging behaviour', 'behaviours that challenge' (Royal College of Psychiatrists et al., 2007) and 'behavioural and psychological symptoms of dementia' (BPSD; Finkel et al., 1997) are the most commonly used in this field, but all have their limitations and critics and well as their supporters. However, the key point from the psychological perspective assumes these overt (or covert) changes in presentation represent unmet needs rather than an inevitable consequence (symptom) of an illness. As such, they are amenable to change if those needs can be identified and met.

It is important to remember that many of the behaviours identified as challenging are not symptoms of dementia, rather they are symptoms of human distress, disorientation and misperception. As such, it seems counterproductive to frequently treat such behaviours through tranquilisation and sedation without first attempting to deal with the distress and cognitive confusion. Indeed, it is important to recognise that because the behaviours are not the inevitable consequences of a disease, we need to be careful not to treat them as if they are – particularly if this involves using problematic drugs.

Current guidance recommends the use of treatments using a non-pharmacological approach in the initial stages of managing these behaviours (NICE/SCIE, 2006; Banerjee, 2009; National Dementia Strategy, 2009). Consequently, psychosocial and behavioral interventions are recommended as a first line treatment of BPSD (NICE/SCIE 2006; NHS Institute for Innovation and improvement, 2011; Banerjee, 2009).

A number of empirical studies have examined whether non-pharmacological approaches can be used as alternatives to medication (Avorn et al., 1992; Meador et al., 1997; Schmidt et al., 2000). Despite some mixed reviews (Nishtala et al., 2008; Forsetlund et al., 2011), it is evident the best controlled of these studies has shown that regular input from a trained clinician can lead to a significant reduction in the use of antipsychotics (Fossey et al., 2006). The protocol underpinning the work of these clinicians has been published by the Alzheimer's Society (Fossey & James, 2008), and the work itself is being extended with a major non-

pharmacological trial called WHELD (Ballard et al., 2009). This programme has undertaken a major revision of non-pharmacological studies and is currently empiracally testing the use of person-centred approaches, exercise regimes, social interaction and the use of systematic medication reviews with respect to the well-being of people with challenges.

In practice, antipsychotic medication is often used as a first-line treatment for behavioural difficulties rather than as a secondary alternative (Alexopoulos et al., 2005; Alzheimer's Society, 2009), despite the evidence that antipsychotic drugs have a limited positive effect and can cause significant harm to people with dementia (Schneider, Dagerman & Insel, 2006; Ballard, Lana, Theodoulou, Jacoby, Kossawakowski, Yu & Juszczak, 2008; Banerjee, 2009). Interventions offered should aim to lessen the distress and harm caused by these difficulties and increase the quality of life of those living with dementia and their carers (Banerjee et al., 2007; Banerjee, 2009).

Implementing behavioural interventions instead of antipsychotic medication could lead to savings of £54.9 million above the cost of the therapy in England alone, resulting in a reduction in side effects such as the occurrence of incidence of stroke and falls (NHS Institute of Innovation and Improvement, 2011), which would result in an increase in the quality of life of people living with dementia.

The policy context

The four UK nations have all published strategies for the care of people with dementia and their carers:

- Living well with dementia: a National Dementia Strategy (England)
- Scotland's National Dementia Strategy
- National Dementia Vision for Wales
- Improving Dementia Services in Northern Ireland.

All these documents emphasise the need to promote a coordinated, evidence-based response to the caring for the increasing numbers of people with dementia.

More recently, the Department of Health in England has stated that the use of antipsychotic medication for people with dementia needs to be reduced. This is based on the work of Banerjee (2009) who reviewed the use of antipsychotic medication in people with dementia on behalf of the Secretary of State for Health. Professor Banerjee noted that of the 750,000 people with dementia in the UK, around 180,000 (i.e. 20 per cent) will be prescribed antipsychotic medication, of whom 36,000 may derive some clinical benefit. However, Professor Banerjee also pointed out that these medications are associated with significant risks. Banerjee estimated that, '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.'

Since Professor Banerjee's report was published in 2009, there have been a number of initiatives to address antipsychotic use. In June 2011, the Dementia Action Alliance was formed and published a 'Call to Action', advocating that all people with dementia who are prescribed

antipsychotic drugs should have their medication reviewed and that alternatives to their prescription should be considered.

In 2011, the Alzheimer's Society responded to the call by publishing a best practice guide for health and social care professionals. The document aims to assist practitioners by providing practical tools for the assessment and management of behavioural and psychological distress in dementia. This toolkit provides guidance on preventative strategies, alternatives to medication, and safer medication prescribing. In Spring 2012, the Royal College of Nursing (RCN) also published a best practice guide in relation to the use of antipsychotics in dementia, and describes a number case examples of alternative approaches to medication use.

What is needed now?

The response to the Dementia Action Alliance's call to action has been positive and has moved understanding of this area of practice forward. As a partner within the Dementia Action Alliance, the British Psychological Society (BPS) also committed to undertake work to further the aims of the Alliance, and specifically to use the psychological expertise of its members to provide information about working with people with dementia. The BPS committed to summarise the information regarding evidence-based non-pharmacological interventions for people with dementia. This work was taken up by the Faculty of the Psychology of Older People, part of the Division of Clinical Psychology, in 2011.

The literature on psychosocial approaches for people with dementia is extensive, and is featured in a number of individual publications and empirical reviews. Much of this evidence also features in best practice guidance such as the NICE/SCIE Clinical Guideline 42 (NICE, 2006) and the Scottish Intercollegiate Guidelines Network guideline 86 (SIGN, 2006). As such, the Faculty's task is not to reproduce these documents and guidelines. Instead, the Faculty decided to:

- review the existing literature on the use of non-pharmacological interventions for people with dementia;
- produce a high level summary of this literature; and
- present this information in a clear and accessible framework.

The underpinning assumption within the psychosocial literature is that distressed/distressing behaviour represents an unmet need. As such, the therapeutic task is to understand what that need is and to address it, in order to enhance the well-being of the person with dementia. If this is successful, then the behavioral changes will reduce and/or the ability for other people to cope with these behaviours will increase.

By focusing on the non-pharmacological literature, the Faculty is not implying that pharmacological interventions have no role for people with dementia. There are a number of documents and frameworks that describe the use of pharmacological approaches, and the Faculty supports their use where appropriate. Rather, the role of the Faculty (and hence the purpose of this document) is to summarise the psychosocial evidence base and advocate for these approaches as part of a holistic package of care for people with dementia.

Equal access to services for people with dementia

When adopting the interventions outlined below it is important to recognise core principles that should be considered to maintain equal access to services as identified by the NICE guidelines. These recommendations are summarised below;

- The person with dementia should not be excluded from any intervention/services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.
- It is vital that health and social care professionals seek valid consent from the individual living with dementia. This should entail informing the person of the options, and their implications, together with checking that the person understands that they can withdraw from a treatment at any time. In cases where the person lacks the capacity to make a decision, the provisions of the Mental Capacity Act 2005 should be followed.
- An assessment of the carer's needs should be completed to inform the intervention plan (Carers and Disabled Children Act 2000; Carers Equal Opportunities Act 2004). Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner (e.g. clinical psychologist, qualified practitioner).

A further priority stipulated by the NICE guidance is the integration and coordination of health and social care services, ensuring that joint planning is maintained and that there is a shared responsibility for the provision and delivery of health and social care for the individual living with the dementia and their carer.

A stepped care model of assessment and intervention

The introduction of the stepped care model in healthcare has provided a framework for organising healthcare delivery in a targeted manner (e.g. from NICE clinical guidelines to the Improving Access to Psychological Therapies programme). Given that there is a large body of literature on psychosocial approaches to dementia, it seems sensible to use a stepped care framework to identify which interventions should be tried and in which order.

The stepped care approach has been used recently in the treatment of care home residents' suffering from anxiety and depression (Dozeman et al., 2012; Alpin et al 2012). In the present context the stepped care model identifies the appropriate interventions that meet the presenting need, reinforcing the message that antipsychotic medication can be implemented as a secondary alternative. The model reinforces the need to ask '**why the behaviour is occurring?**' and has been informed by research such as Moniz Cook, Swift, James et al. (2012), the work of Cohen-Mansfield et al. (2007) on non-pharmacological interventions for BPSD; Guidelines (Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007; NICE/SCIE 2006) and Government sponsored reports (Banerjee, 2009; European Union, 2009).

The steps describe the level of assessment and treatment input, identifying the person/professional that can perform the task. The interventions range from the initial

identification and treatment of physical causes (Step 1), understanding the person in more detail and getting the care environment right (Step 2), protocol-driven interventions tailored to specific presentations (Step 3), and intensive individualised psychological formulation-led interventions identified for more complex presentations (Step 4). While specific non-pharmacological interventions are first mentioned at Step 3, they may occur at any step.

The model is not intended as a rigid pathway, but it is intended that step 1 is undertaken first. After this, it is pragmatic to undertake the next steps in order, unless otherwise indicated.

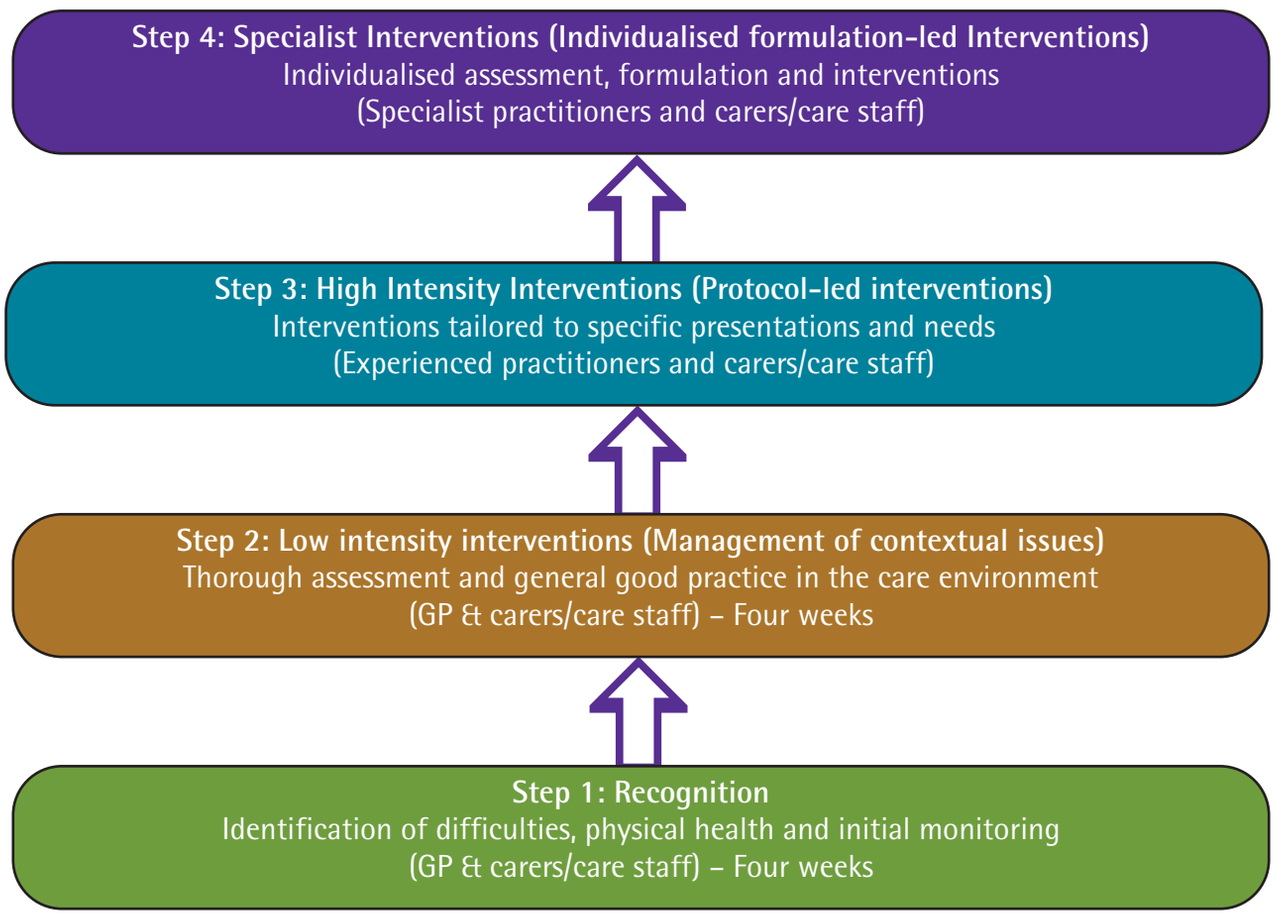

Figure 1: The stepped care model

However, an individual with dementia may present with particular behaviours that require a higher intensity of intervention and as such the person can be stepped up. The model provides sign posts to interventions that meet individual need with the aim of preventing further increase in distress for the individual and the carer. However there is the opportunity for movement from one step to another if the behaviour continues to be unresolved.

Step 1: Recognition

This step is focused on identifying that there is an issue for the person that may relate to the dementia, and recommends taking initial steps to assess and treat commonly occurring causes of distress and behaviour change. As such, all individuals should be initially assessed at this level.

Step 1: Recognition
Identification of difficulties, physical health and initial monitoring
(GP & carers/care staff) – Four weeks

Assessing Causes and Risks

Recognition of physical causes

- Screen for treatable conditions that may be either causing or contributing to confusion and distress, such as: delirium, pain, seizures, vascular events, diabetes, constipation, infections, thyroid disturbance, poor sleep, sensory loss, alcohol misuse, other medical conditions.
- Screen for presence of psychosis, depression, anxiety.
- Screen for negative impact of medication, including interactions/side effects (e.g. some statins causing agitation, Parkinson's medication causing disinhibition).
- If not a physical issue, proceed to step 2

Assess risk issues for client and carer(s).

Actions

- Treat common physical causes and inform family/carers about signs, symptoms, preventative measures for these conditions.
- If a risk identified, step up (low risk = step 2, high risk = step 3 or 4)
- Do not prescribe antipsychotics at this stage, unless psychosis evident in absence of Dementia with Lewy Bodies.
- Adjust medication if required to avoid unwanted interactions/side effects.
- Ask carers to monitor behaviours for four weeks (e.g. try to identify patterns – an example chart is given in appendix 1).
- Provide good practice checklist – an attempt to understand the person/information prescriptions/guided reading for carers.
- Provide information for carers (e.g. Alzheimer's Society website).
- If carer distress is identified, signpost to voluntary organisations/dementia advisors. If distress severe consider referral for carer's assessment, referral to other support (e.g. support group, local IAPT service).

Assessing the causes and risks

Objective 1 of the National Dementia Strategy in England states that an early comprehensive assessment for people with dementia should include:

- the person's physical health;
- depression;
- possible undetected pain or discomfort;
- side effects of medication;
- individual biography, including religious beliefs and spiritual and cultural identity;
- psychosocial factors;
- physical environmental factors; and
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers (NICE 2007).

At this initial stage, the starting point should be an assessment in primary care (for example, by a General Practitioner) to identify and treat any potential physical contributors. This should involve screening for: delirium, pain, diabetes, constipation, infection, sleep disturbance, and other medical conditions. Consideration should also be given to the person's medication regimen and the possibility of drug interactions and side effects. In recent years there has been a particular emphasis on the identification of pain (Woods & Moniz-Cook, 2012), and the realisation that it can play an important role in the distressed behaviour of people with dementia. A useful tool for assessing pain in dementia, which is notoriously difficult to identify, is the Abbey pain questionnaire.

Finally, the GP should assess for mental health issues such as psychosis, depression and anxiety. At this point, the assessment in itself can be an enough to identify and relieve the presenting difficulties.

Actions

The main focus is to treat common physical causes of the behaviours and adjust medication if required to avoid unwanted interactions/side effects. It is not necessary to prescribe antipsychotics at this stage unless there is evidence of psychosis (except for the case of Dementia with Lewy Bodies – DLB) or there is severe distress for the client or immediate harm to the client and/or others (note: relevant prescribing guidelines should be consulted).

The Alzheimer's Society (2011) has produced guidance for health and social care staff that outlines some initial interventions that can be considered at this step. These include:

- Understanding the individual needs of the person with dementia, as it can affect people in different ways. There is not a 'one-size-fits-all' care strategy.
- Recognising triggers and early signs that may precede the behavioural difficulties is crucial as in most cases simple approaches to early signs can prevent the symptoms developing at all.
- Watchful waiting – asking carers to monitor and record behaviours over four weeks (e.g. try to identify patterns). Many difficulties will stop after this period without pharmacological treatment.
- Providing information leaflets, guided reading and good practice checklists (available

from a number of sources, including the Alzheimer's Society website). The use of these types of information in a one-to-one setting to care givers has been found to reduce the BPSD (Livingstone et al., 2005).

- For people with significant language or communication difficulties, consider using the Distress Thermometer and/or asking a family member or carer about symptoms; if significant distress is identified, investigate this further.

If a degree of **risk** to the person or others is identified, consider moving on to step 2. If high levels of risk are identified, move up to step 3 or 4 depending on the circumstances and the judgement of the health/social care professional.

Needs of carers

At this stage, it is also important to identify potential carer needs. The difficulties faced by the person with dementia will also impact on their families, and carer distress is one of the reasons people's relatives are admitted to long-term care (European Union report, 2009). Objective 3 of the National Dementia Strategy identifies the need to provide carers with good quality information regarding the condition. However, the Alzheimer's Society (2010) indicates that, despite good information being available, 'people report that their needs are not met or that information is provided too late or not at all. A key problem is that people have to ask for information, rather than it being provided proactively. Most people do not know what they have to ask for.' As such, carers should be routinely offered sources of information regarding dementia, how it presents and how to manage it (for example, information leaflets from the Alzheimer's Society website), as well as where to seek help and assistance if required.

If carer distress is identified then consideration should be given to signposting to voluntary organisations/dementia advisors. If the level of distress is severe, consideration should be given to a referral for carer's assessment (as required by the Carer's Act), and/or referral to other support (e.g. support group, local IAPT service). Carers who experience anxiety and/or depression are entitled to evidence-based treatments under current NICE guidance for those presentations.

The complex range of services and staff with whom people with dementia and carers are in contact with can be confusing. It is unclear which professional can provide particular pieces of information and no one professional has responsibility for providing the full range of information. This leads to unhelpful gaps. While a more recent report (Health Foundation, 2011) highlights a further difficulty encountered by carer's from services and staff in terms of not sharing information with them about important developments in their relative's life and transition points between services.

When working with staff in wards and care homes it is important to acknowledge and support their existing skills. This is because by virtue of the sheer prevalence of behaviours that challenge, the staff are generally skilled in the treatment of most problematic behaviours they encounter. These skills normally take the form of good communication and interactive styles, verbal and non-verbal approaches. Accepting this existing skill-base, one might then start to explore 'why' in this particular case the staffs' normal approaches are not working effectively; sometimes this may be due to an inconsistent approach between the members of the staff team (James, 2011).

Step 2: Assessment and treatment of contextual issues

At step 1, common physical causes of the behavioural difficulties should have been ruled out. Therefore, step 2 focuses on further understanding of the needs of the individual in their environment and introducing general, good practice interventions within that environment.

By their nature, behavioural difficulties tend to require some form of interaction between the person with dementia and a carer. For example, the carer may need to encourage the person to get out of bed, take medication; or the carer may need to intervene to prevent a problem behaviour becoming risky. As such, good practice requires the use of good interactive and communication skills on the part of the carer. Indeed, audits of interventions carried out by the Newcastle Challenging Behaviour Team (James, 2011) reveal that a key factor in determining the resolution of problematic behaviours is the quality of the interaction of the carers with the person with dementia. Further, those who interact well tend to be good communicators, taking account of the needs and current perceptions of the person with dementia.

Staff and carers require some level of training and support to deliver interventions at this step, but this is at the level of good dementia awareness rather than specialist training. In terms of enhancing communication with the person with dementia, there is a growing literature on improving carers' communication skills (Levy-Storms, 2008; Eggenberger et al., 2013).

Assessing the presentation in context

Objective 1 of the National Dementia Strategy states that an early comprehensive assessment for people with dementia should include:

- the person's physical health;
- depression;
- possible undetected pain or discomfort;

Step 2: Low intensity interventions (Management of contextual issues)
Thorough assessment and general good practice in the care environment
(GP & carers/care staff) – Four weeks

Assessing the presentation in context

Assess and review the following:

- Behaviour records (what, when, who with, etc.).
- Emotional status of the client (e.g. assessing emotions, moods, worries, beliefs).
- Physical environment (e.g. overcrowding, privacy, noise levels).
- Carer communication skills and style of interacting.
- Communication (can the person communicate what they want, and can others communicate with them?).
- Design and layout of environment.
- Social contact (opportunities to spend meaningful time with others).
- Occupation (i.e. how is the person spending their time).

Actions

- Do not prescribe antipsychotics unless psychosis evident (in the absence of DLB).
- Choose intervention on the basis of the assessment:
  (i.e. general interventions within the care environment).
  - Dementia awareness training for staff.
  - Develop carer communication and interaction skills.
  - Developing life histories.
  - Engagement in meaningful activity/social programme (e.g. reminiscence group)
  - Changes to the physical environment/layout.
  - Frameworks to help understanding the emotional impact the person with dementia can have on the carer and vice versa (eg. emotional triads; James, 2011).
- Carers to monitor behaviours for four weeks - e.g. try to identify patterns
  (see appendix 1 for an example form). If no change in behaviour, proceed to step 3.

- side effects of medication;
- individual biography, including religious beliefs and spiritual and cultural identity;
- psychosocial factors;
- physical environmental factors; and
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers (NICE 2007).

If assessment has taken place appropriately at step 1, then the first four points on the above list should have been addressed. Practitioners should remain mindful of these areas, but at step 2 more emphasis is given to the next four areas.

Everyday experience tells us that people interpret situations and behaviour differently, and this is just the same with behavioural changes in dementia. Research evidence also shows that there can be low levels of agreement amongst senior staff regarding what constitutes behaviour that challenges (Bird & Moniz-Cook, 2008), adding further complexity to the assessment process. Therefore, it is important to have some objective understanding of exactly what is happening.

As such, the first task is to have clear records of exactly what is taking place, how often, and whether this is causing difficulty and/or distress for those involved. There are specific tools available to help with the recording of such information (e.g. Challenging Behaviour Scale; Moniz-Cook, 2001 – Appendix 2), and the key areas to address include:

- **What** is the individual saying or doing? What are his/her current beliefs about the present situation? (e.g. Does Mrs Smith believe she is in her 30s, caring for young children and an elderly mother? Does Mr Jones believe he's a joiner, single, and currently living in a hotel?). How is the person expressing themselves, are they angry; scared; crying; confused?
- **When** has the behaviour occurred? Consider at what time of day it is, what is going on at the time (e.g. is it meal-time; bed-time; when the person requires assistance; when they are alone/with others?)
- **Where** has it happened?
- **How** often is it happening?
- **Who** is it causing distress for (i.e. the person themselves, others)?

It is also important to understand the context in which these behaviours are occurring, specifically the environment in which the person is living in and what is going on.

- What is the **emotional** status of the individual? Is the person communicating any worries/fears/concerns, are they lower in mood? In situations where the individual is unable to communicate what information do you know from their past to inform your understanding and/or explain their behaviour?
- What are the **physical features** of the environment? Overcrowding, lack of privacy, noise levels, etc., can have a significant impact on an individual's ability to interpret their environment. If an individual is over or under-stimulated this can have a negative impact.
- **Communication**. Can the person easily communicate what they want/need? If not, how do they let people know if they are hungry, thirsty, in pain, lonely, afraid?
- The **design and layout of the environment** can either assist or confuse. Is it easy for someone to find their way around? It is easy to identify where the toilets are/where you can get a drink? Where can the person find other people to speak to?
- **Social contact** (opportunities to spend meaningful time with others) forming relationships, sharing life experiences and their home environment help to allow a shared ownership of the home, and create a positive sense of self.
- **Occupation** (i.e. how is the person spending their time) is vital when we consider an individual's sense of self worth. Lack of meaningful occupation can lead to sensory deprivation, boredom, isolation and low mood. It is important that the person living with dementia continues to experience their identity, have a sense of purpose, and role in their home environment.

A summary of methods used to obtain such information is provided in Fossey and James (2008). The publication outlined non-pharmacological approaches to be used in the place of psychotropic medication.

By assessing what is happening and the context in which it is happening, it is possible to understand the current experiences of the person with dementia. An important feature of this is an appreciation of his/her current beliefs and thoughts regarding his/her current situation, because these cognitions will often drive the behaviours. In the case of Mrs Smith (outlined above), her conviction that she has got children and a elderly mother may result in her forcibly attempting to leave her care home of an evening to try to collect her children from school. Mr Jones, believing himself single, may become sexually dis-inhibited when young female carers try to give him a bath. Hence, by understanding the person's beliefs and other contextual features we will be able to relate and communicate with the person better.

Actions

As identified in step 1, it is not necessary to prescribe antipsychotics at this stage unless there is evidence of psychosis (except for the case of Dementia with Lewy Bodies – DLB where antipsychotics should not be used) or there is severe distress for the client or immediate harm to the client and/or others (note: relevant prescribing guidelines should be consulted).

The findings from the assessment will determine the interventions that can be considered. Outlined below are a number of interventions than can be considered.

- **Improve staff communication with the person with dementia:** Encourage staff to interact with the person, getting to know them as a person and to have appreciation of the person's past. This is because people with dementia can become 'time-shifted' and their current behaviours may be reflection of previous episodes and roles in their lives. Also encourage staff to use good verbal and non-verbal skills, looking for clues to what the person with dementia is thinking and trying to communicate. Support staff in attempting to meet the person with dementia's needs (Cohen-Mansfield, 2000; James, 2011).
- **Dementia awareness training:** The use of staff dementia awareness training on the management of the behaviour that challenges has shown reductions in the occurrence of the behaviour for several months (Livingstone et al., 2005; Lai et al., 2009), and a reduction in use of antipsychotics (Fossey et al., 2006).
- **Life Story:** The development of a life-story booklet provides families and carers an opportunity to deliver person-centred care by placing the individual and their biography at the heart of their own care. A life story book explores the life history of the person with dementia and can support the delivery of new ways of working with people living with dementia (e.g. DoH-funded project with the Life Story network).
  It provides people with a practical set of tools to help them engage with the real person and see them beyond their illness, disability or diagnosis.
- **Use of memory/activity boxes:** The use of these boxes promotes better quality communication between the person with dementia and their carer. The box combines life story work, reminiscence and cued retrieval techniques. Typically carers and friends of the person with dementia are asked to populate the box with items that are known to cue positive memories. The contents often include favourite books, possessions, memorabilia ornaments, photographs, etc.
- **Meaningful occupation:** Engagement in meaningful activity such as reminiscence group work, can improve the mood of people with dementia, without any reported harmful side effects (RCN, 2011; Woods et al., 2009). Such activities also increase levels of social interaction (see below)
- **Social interaction:** Increasing social contact is effective in enhancing well-being and reducing distress (Levy-Storm, 2008). Eggenberger et al. (2013) provide a list of useful communication strategies based on their systematic review of interactions with care home settings.
- **Physical environment:** Changes to the physical environment for the person with dementia can trigger the onset of behaviours that challenge. Identifying the trigger can alleviate distress for the person living with dementia (Pointon, 2001). The use of horizontal grid patterns can reduce attempts to open doors (Hussain & Brown, 1987), blinds and cloth barriers placed over doors/door handles (Namazi et al., 1989) have also been evidenced as effective methods for reducing distress. Evidence suggests that making changes to the physical environment to make it 'dementia friendly' is an effective intervention to reduce distress in individuals living with dementia (RCN, 2011).

After **two to four weeks** (or the end of the intervention) some change should have occurred. If there is no reduction in the frequency of the behaviour or the caregiver is experiencing difficulties managing the situation, the assessment and plan should be reviewed and revised as required. If no further chance is evident by **four–six weeks**, it would be appropriate to proceed to step 3.

Step 3: High Intensity Interventions

At this stage, more intensive assessment and interventions are focused on specific needs and presentations. These are less focused on the general environment, and more on specific issues/needs that commonly arise in the context of dementia (e.g communication, memory, interpersonal interactions). These assessments and interventions require specific training on the part of those delivering them.

Assessing needs in relation to patterns of presentation

At this step, health and social care staff who are specifically trained and appropriately clinically supervised in the chosen protocol-led intervention are to take the lead, in line with Objective 1 of the National Dementia Strategy. Although the strategy makes reference to 'behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers' (NICE, 2007), other suitable assessment and intervention protocols are included here. A review of the clinical frameworks is provided by James (2011), highlighting the work of Kitwood (1997), Kuniks et al. (2003) Volicer and Hurley (2003) and Cohen-Mansfield (2000).

Step 3: High Intensity Interventions (Protocol-led interventions)
Interventions tailored to specific presentations and needs
(Experienced practitioners and carers/care staff)

Assessments and actions targeted at presentations rather than at the level of the individual assessing needs in relation to patterns of presentation

- Use of structured protocols to assess needs and determine interventions; e.g.
  - TREA model – Treatment Routes for Exploring Agitation (Cohen-Mansfield, 2000);
  - Dementia Care Mapping (Bradford Dementia Group); and
  - Behaviour records (ABC charts) .
- Systematic review of information from earlier steps (medical review, mental well-being, history, physical environment, social and occupational environment) to identify potential determinants of behaviour .

Actions

Tailoring the intervention to the diagnosis and presentation (agitation, boredom, vocalising), and use of decision trees to guide choice of interventions.

- Interventions could include: behaviour management advice, TREA, communication skills training, aromatherapy.
- Some interventions are particularly useful for improving quality of life and mood but are less suitable for the acute treatment of agitated behaviours. However, these interventions may form an important element of a combined treatment package: e.g. dementia care mapping, reminiscence therapy, cognitive stimulation, music, psychomotor & exercise, staff training in high quality interaction
- If there is high risk to self or others, consider medication (in line with appropriate prescribing guidelines).

Specific assessment frameworks will be deployed at this step, some of which link to specific intervention packages. For example, protocol decision trees are used in the TREA model, directing the practitioner to investigate six domains: (1) pain or discomfort, (2) need for social contact, (3) appropriate level of stimulation, (4) hallucinations, (5) depression and control, and (6) poor communication (Cohen-Mansfield et al., 2007). The findings from the assessment are used to determine a specific behaviour management intervention.

Kunik's Model of Behavioural Problems (Kunik et al., 2003) describes a multidimensional model of problematic behaviours. They suggest that there are three aspects that one must examine when accounting for such behaviours, namely features associated with the person, the caregiver, and the environment. Each of these aspects is then divided further into fixed and mutable determinants. Fixed determinants are characteristics that are difficult or impossible to change, while mutable characteristics can be altered via the efforts of therapists, family and staff, etc.

Dementia care mapping (DCM, developed by the Bradford Dementia Group; Kitwood, 1997) provides a structured framework for assessing interactions between caregivers and people with dementia, recording the type and frequency of different classes of interaction. This information is used to enhance the use of positive interactions and increase the well-being of people with dementia.

Behavioural records can also support decision-making at this point, particularly ABC charts (Antecedent, Behaviour, Consequence charts). These can identify patterns in behaviours and likely triggers by recording what happens before, during and after an occurrence of the behaviour, and can be helpful in determining the likely cause of the behaviours. At this stage, it is important that these records are reviewed by someone with training in behavioural assessment and management. Behavioural management programmes can then be derived from this information in order to shape behaviour. Again, these should be designed by someone experienced in the use of behavioural management techniques.

In addition, information ascertained from earlier steps (i.e. medical review, mental well-being, history, physical environment, social and occupational environment) should be reviewed to try and identify potential determinants of behaviours.

Action

Tailoring the intervention to the diagnosis and presentation (agitation, boredom, vocalising), and use of decision trees to guide choice of interventions. This could include:

- Behavioural management: Based on learning theories, behavioural management approaches from a trained practitioner can be of value in helping direct and shape behaviours that are harmful and/or distressing. Moniz-Cook's et al (2012) Cochrane review on functional analytical techniques identified 15 quality studies in this area, showing an encouraging evidence base.
- Staff training in improving communication and quality interaction and reminiscence work has been demonstrated to produce improvement in the BPSD too (see step 2; Woods, Spector, Jones, Orrell & Davies, 2009; Lai et al., 2009; etc.). A good example of a person centred staff training programme was provided by David Sheard, in the BBC documentary series *Can Gerry Robinson Fix Dementia Care Homes?* (BBC, 2009)
- Treatment route to exploring agitation (TREA, Cohen-Mansfield, 2000): this approach uses a decision-tree framework, which uses empirical data to identify the likely cause of a particular behaviour (e.g. verbal agitation – pain, sensory difficulties, lack of social contact, etc), and then suggests relevant interventions.
- Aromatherapy, in particular Melissa essential oil, has been identified as effective in reducing wandering and agitation in severe dementia in double-blind, placebo-controlled trials (Robinson et al., 2007; Ballard et al., 2002). However, recent results have not been as positive.

Other methodologies are useful in dealing with mood and quality of life issues, but do not necessarily target agitated forms of behaviours. However, these methods can often be part of a package of care:

- **Dementia care mapping (DCM):** Randomised controlled trials show that this approach was effective at reducing agitation in people with dementia (Chenoweth et al., 2009, cited in Ballad & Corbett, 2010; Brooker, 2005)
- **Cognitive Stimulation Therapy (CST):** Research trials have shown significant improvements in a range of cognitive functions as well as a reduction in aggressive or problem behaviours (NICE/SCIE 2006; Olazaran et al 2010; Ballard et al., 2011). A comparison of the health economics of cognitive stimulation therapy versus antipsychotic medication by the NHS Institute (NHS Institute, 2011) reported that £70.4 million in health cost savings would be generated by the adoption of behavioural interventions over antipsychotic use (p.9).
- **Psychomotor and exercise interventions** that are performed several times a week for 30-minute periods, that include walking, can produce improvements in mood and the quantity and quality of sleep in people with dementia (Eggermont & Scherder, 2005). The Seattle studies (Teri et al., 2008) have undertaken a major programme of work on the impact of exercise on people with dementia, and demonstrated significant benefits in terms of agitation.
- **Music** as an active (client plays a part in music making) or receptive (client listens to music) intervention in both individual and in group settings has some evidence of a positive effect in reducing the occurrence of agitation, aggressive behaviour and

wandering. (Vink et al., 2011). Cohen-Mansfield (2001) has produced a helpful taxonomy for the non-pharmacological approaches. She used it in her systematic review in which she identified 83 psychological interventions. Her classification is composed of eight types of interventions: sensory, social contact (real or simulated), behaviour therapy, staff training, structured activities, environmental interventions, medical/nursing care interventions, and combination therapies.

- **Medication:** The use of medications as an intervention for problematic behaviours is beyond the scope of this paper, but traditionally attempts to manage these behaviours involve the wide use of antipsychotic drugs (Schneider et al., 2006). Antipsychotic medication in particular should not be used for mild to moderate BPSD because of severe adverse risk reactions and the modest benefits (Ballard, Sharp et al., 2008; Banerjee, 2009). The widespread prescription of antipsychotics as a first line treatment for people with dementia continues, even though both the evidence and recommendations from the Committee on Safety of Medicines (the predecessor to the Commission on Human Medicines) run contrary to this (Ballard, Sharp et al., 2008). The NICE/SCIE guidance recommends that antipsychotic drugs be used for BPSD as a first line response only when there is severe distress or an immediate risk of harm to person with dementia or others. If antipsychotics are prescribed treatment should only be continued beyond 12 weeks in exceptional circumstances. (See Ballard and Corbett, 2010 for a review of the pharmacological interventions for BPSD.)

Step 4: Specialised Interventions

At Step 4, highly individualised assessments and interventions are undertaken that focus specifically on the individual and use specific psychological frameworks to understand their individual experience and needs. At this level, specialist training is required in specific theoretical approaches, assessment techniques and tailored interventions. In many circumstances when working at Step 4, the agents of change are the carers, and as such many of the interventions involve getting the carers to adopt new approaches and a different style of interaction with the person with dementia. To do this effectively, therapists with specialist training are required because skills in family therapy, group therapy, CBT, psychodynamic approaches are often useful when working with the carers.

Although primarily psychological in nature, these interventions will often occur in a multidisciplinary setting and a range of specialist perspectives will be integrated into a biopsychosocial formulation of the individual.

Step 4: Specialist Interventions (Individualised formulation-led Interventions)
Individualised assessment, formulation and interventions
(Specialist practitioners and carers/care staff)

The development of an individually-tailored intervention based around an individualised biopsychosocial formulation

Assessing Needs

Specialist Practitioners

- Full functional analysis
- Biopsychosocial formulation

Actions

Management plan (routinely monitored) which may include:

- Psychological interventions
- Social and occupational interventions
- Medication (can include antipsychotics if indicated)
- Regular specialist reviews

Assessing needs

At this step only staff specifically trained and appropriately clinically supervised to deliver idiographic formulations should take the lead at developing individually tailored interventions. Specialist practitioners may do this from a range of models or perspectives, for example full functional analysis or idiographic biopsychosocial formulation (such as Cohen-Mansfield's unmet need approach, 2000; Comprehensive model of psychiatric symptoms of progressive degenerative dementia, Volicer & Hurley, 2003; the Roseberry Park model, Dexter-Smith, 2010; Newcastle Columbo model, James, 2011). The end result, however, would be an individually tailored intervention that is specific to the person with dementia, the carers and environment. It is important to highlight that the above formulations are structural frameworks and it is the skill with which they are employed with the carers (i.e. the process features associated with the

models) that determine the success of the interventions. All of the models described above contain descriptions of how they should be used and employed and it is important that these protocols are used
(see James, 2011).

Often, but not exclusively, clinical psychologists can take a lead with these formulation-led approaches. This is because while other professional groups produce formulations, (for example, formulation features in the curriculum for psychiatrists' training, Royal College of Psychiatrists, 2010), psychologists receive the most in-depth training in psychological theory and formulation. Thus, they are often well-placed to promote its use through practice, teaching, supervision, consultancy and research. From an organisational perspective the grounding, training and experience of a psychologist can provide mental health teams with a unique coherent alternative to the medical model (Onyett, 2007) which can help teams take the conceptual leap away from the use of antipsychotics.

Action

The interventions employed at this step may bear some similarities to those used at Step 3, but they will be derived from the idiosyncratic formulation rather than a manual-based treatment protocol from a single theoretical perspective. Although the list of actions appears shorter than in previous steps, the reality will be that more professionals are involved in the care of the person, deploying more specialist knowledge and expertise.

The formulation will have identified the clients' needs and their current (hypothesised) thinking patterns, and the interventions will be specifically tailored to meet a person's needs (i.e. to facilitate communication, reduce anxiety, promote independence, and relieve boredom or pain). In those circumstances where the person's needs cannot be met directly, the therapist may attempt to substitute the need via the introduction of some alternative feature (for example, if the person is asking for his deceased wife, a simulation presence DVD of his family may be used). On occasions, the therapist also might try to shift the person's perspective to create a more achievable goal (e.g. to ask the person if he would like to see his sister). In some circumstances, the therapist may have to concur with the client's erroneous view of reality and work from this perspective in order to reduce agitation or distress (for example, go along with the person's belief that his wife is still alive).

It is also essential at this stage that all aspects of a person's care are reviewed. As such, the management plan will need to be routinely monitored by the specialist team involved. The reviews should include:

- psychological interventions;
- social and occupational interventions;
- medication (can include antipsychotics if indicated) and
- regular specialist reviews.

Carers

The needs of carers will again come to the fore at Step 4. As described in detail in Step 1, carer needs should be assessed and signposting, support and treatment should be made available (see page 8). However, it should also be borne in mind that the carer will probably be intimately involved in delivery of the interventions at Step 4, and the professional team will be engaging with the carer on a regular basis to this end. As such, the professionals involved will

need to be mindful of the carer's state of well-being and their ability to cope with the situation, so that support can be offered as required. In Moniz-Cook et al.'s (2012) Cochrane review there are a number of examples of studies that have employed carer interventions to good effect. Examples of successful programmes includes the STARs framework (Teri et al., 2005). The use of CBT and acceptance and commitment therapy also show promise (Marriott et al., 2000; Márquez-Gonzalez et al., 2010).

Prescribers

Wood-Mitchell et al. (2008) demonstrated that there are numerous factors that maintain psychiatrists' prescribing practices and, in some cases, their preferences for using medication. On the positive side the psychiatrists seemed to be aware of best practice biopsychosocial methods, yet were sceptical of their efficacy and the staff's ability to carry them out effectively.

Such findings suggest that psychiatrists, GPs, and other medical professionals need to educated in the use of non-pharmacological methods, and also be part of the broad training programmes required to teach care staff to use the methods effectively.

Summary

1. The majority, if not all, of people living with dementia are likely to experience behavioural and psychological difficulties at some point during their illness. This is because the behaviours reflect people's attempts to fulfill their needs and thus they are a natural consequence of being alive.

2 In the past the problematic behaviours were treated as if they were symptoms of dementia, which suggested that they had a clear discernable aetiology. This view led to the prescribing of specific types of medication for different behaviours (i.e. use of the medical model). However, most clinicians now accept that the behaviours are products of a range of biopsychosocial features (e.g. distress, disorientation, misinterpretation, psychosis, pain, delirium, etc.), and are not unique to dementia. As such, it is evident that there is no 'magic bullet' with respect to the treatment of the behaviours rather clinicians are required to obtain a understanding of the biopsychosocial causes.

3. Current guidance recommends the use of non-pharmacological approaches in the initial stages of managing these difficulties, but in reality antipsychotic medication is often used as a first line treatment. Implementing behavioural interventions could lead to savings of £54.9 million above the cost of the therapy, resulting in a reduction in side effects such as the occurrence of incidence of stroke and falls in people with dementia.

4. The stepped care model discussed in this document reinforces the need to ask 'why the behaviour is occurring?' and 'who is it distressing for?' (i.e. doing a good assessment). This places the behaviour in the context of the person's life history and the social and physical environment in which they live, and shapes the intervention required. In the future greater care will need to exercised in the prescribing of such medication outside of accepted guidelines, because their limited effectiveness and numerous side effects may lead families to question whether these drugs are being used in their relative's 'best interests'.

5. The model is intended to guide the delivery of care, and it is generally intended that individuals would work their way through individual steps (i.e. choosing the least invasive/intensive interventions first). However, the person's individual situation and needs may require that they 'miss out' some steps and proceed to a higher step, and this is entirely appropriate.

6. Do not prescribe antipsychotics unless (i) psychosis is evident (except in the case of Dementia with Lewy Bodies), (ii) there is severe distress for the client; or (iii) immediate harm to the client and/or others. If antipsychotics are prescribed they should follow good practice using target, titration, and time, and should be reviewed with a view to discontinuation at the earliest opportunity.

7. There is not a 'one-size-fits-all' care strategy: people are individuals and so the reasons for their behaviour do vary. Therefore, watchful waiting, asking carers to monitor and record behaviours over a period of weeks (e.g. to try to identify patterns) to test out strategies and the success of individualised approaches is essential. Most behavioural difficulties will stop after four weeks without pharmacological treatment (Alzheimer's Society, 2011).

8. Clinical psychologists receive the most in-depth training in using psychological theory and evidence, and have a great deal of experience in applying this knowledge in clinical situations. As such, this staff group possess knowledge, skills and experience that complements the medical model (Onyett, 2007), and can be instrumental in helping teams take the conceptual leap away from the use of antipsychotics.

9. The stepped care model is applicable to acute and general hospital settings by helping to provide a framework and guidance around improving the quality of care for people with dementia and thus reducing the length of stay in hospital settings.
Up to 60 per cent of acute hospital beds are occupied by older people, approximately 40 per cent of whom have dementia. However, patients who have dementia experience many more complications and stay longer in hospital than those without dementia.

10. When adopting the interventions outlined it is important to recognise core principles that should be considered to maintain equal access to services. Namely that the person living with dementia should not be excluded from any intervention/ services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.

11. The integration and coordination of health and social care services should be promoted to ensure that joint planning is maintained and that there is a shared responsibility for the provision and delivery of health and social care for the individual living with the dementia and their carer.

Glossary

Alzheimer's Society: The leading support and research charity for people with dementia, their families and carers. It is a membership organisation, which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland through a range of activities, by providing a network of local services, research, publications and factsheets.

Antipsychotic medications/drug: The name given to a group of medications that is usually used to treat people with psychosis. It is also frequently prescribed to people with dementia to manage the BPSD.

Aromatherapy: A form of alternative and complementary medicine based on the use of very concentrated 'essential' oils from the flowers, leaves, bark, branches, rind or roots of plants with purported healing properties. In aromatherapy these potent oils are mixed with a carrier (usually soyabean or almond oil) or the oils are diluted with alcohol or water and rubbed on the skin, sprayed in the air, inhaled or applied as a compress.

Behavioural and psychological symptoms of dementia (BPSD): The term given to people living with dementia who experience development of behavioural and psychological difficulties at some point during their illness. Also known as 'behaviour that challenges' and 'neuropsychiatric symptoms of dementia'.

Cognitive stimulation therapy (CST): A brief treatment for people with mild to moderate dementia. Treatment involves sessions of themed activities running a few times a week over a period of several weeks. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. CST can be provided irrespective of drug treatments received.

Dementia care mapping (DCM): An observational tool designed to assess the quality of life of people with dementia with the aim of promoting patient focused holistic practices.

Dementia with Lewy bodies (DLB): Dementia is a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities. DLB is one type of dementia where abnormal protein deposits develop in nerve cells in the brain. These deposits or structures are known as Lewy bodies.

Formulation: A formulation aims to explain, on the basis of psychological theory, the development and maintenance of the service user's difficulties, at this time and in these situations; summarise the service user's core problems; suggest how the service user's difficulties may relate to one another, by drawing on psychological theories and principles; indicate a plan of intervention which is based in the psychological processes and principles already identified; and is open to revision and re-formulation (Johnstone & Dallos, 2006.

Improving Access to Psychological Therapies: An NHS programme rolling out frontline psychological services, combined where appropriate with medication which traditionally had been the only treatment available, across England offering interventions approved by the National Institute of Health and Clinical Excellence (NICE) for treating people with depression and anxiety disorders.

National Institute of Health and Clinical Excellence: Develops evidence-based guidelines on the most effective ways to diagnose, treat and prevent disease and ill health. They produce

guidelines for professionals to inform practise as well patient-friendly versions of their guidelines to help educate and empower patients, carers and the public to take an active role in managing health conditions.

Reminiscence therapy: Involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of tangible prompts such as photographs, household and other familiar items from the past, music and archive sound recordings.

Treatment routes for exploring agitation (TREA): An objective, systematic method for developing individualised non-pharmacological treatment plans based on an analysis of the agitated person's unmet needs, past and current preferences, past role-identity, cognitive, mobility, and sensory abilities/limitations, and possible causes for particular agitated behaviours. The methodology calls for ascertaining the type of agitated behaviour and the most likely aetiology, and then matching the intervention to the aetiology and to the participant's characteristics.

Randomised controlled trial: Where people are allocated at random (by chance alone) to receive one of several clinical interventions. One of these interventions is the standard of comparison or control. The control may be a standard practice, a placebo, or no intervention at all.

Social Care Institute for Excellence: Improves the lives of people who use care services by sharing knowledge about what works. It is an independent charity working with adults, families and children's social care and social work services across the UK. It also works closely with related services such as health care and housing. It gathers and analyses knowledge about what works and translates that knowledge into practical resources, learning materials and services for use by those working in care services. This includes managers, frontline staff, commissioners and trainers. People and their families who use these services can also use these resources.

Watchful waiting: An active process that over a defined period of time involves an ongoing assessment of contributing factors and simple non-drug treatments. It is the safest and most effective therapeutic approach unless there is sever risk or severe distress (Alzheimer's Society, 2011).

References

All-Party Parliamentary Group on Dementia (2010). *A misspent opportunity: Challenging the dementia skills gap*. London: Alzheimer's Society.

Alexopoulos, G.S., Jeste, D.V., Chung, H., Carpenter, D., Ross, R., & Docherty, J.P. (2005). The expert consensus guideline series. Treatment of dementia and its behavioral disturbances. Introduction: methods, commentary, and summary. *Postgraduate Medicine*, 6–22.

Alzheimer's Society (2009). *Counting the cost. Caring for people with dementia on hospital wards*. London: Alzheimer's Society.

Alzheimer's Society (2010). *Information needs of people with dementia and their carers*. London: Alzheimer's Society.

Alzheimer's Society (2011). *Optimising treatment and care for people with behavioural and psychological symptoms of dementia – A best practice guide for health and social care professionals*. London: Alzheimer's Society. Available from http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=609.

Ballard, C., O'Brien, J., James, I. & Swann, A. (2001). *Dementia: management of behavioural and psychological symptoms*. Oxford: Oxford University Press.

Ballard, C.G., O'Brien, J.T., Reichelt, K. & Perry, E.K. (2002). Aromatherapy as a safe and effective treatment for the management of agitation in severe dementia: the results of a double-blind, placebo-controlled trial with Melissa. *Journal of Clinical Psychiatry, 63*(7), 553–558.

Ballard, C.C. & Cobett, A. (2010). Management of neuropsychiatric symptoms in people with dementia. *CNS Drugs, 24*(9), 729–739.

Ballard, C., Lana, M.M, Theodoulou, M., Douglas, S., McShane, R., Jacoby, R., Kossakowski, K., Yu, L.M., Juszczak, E. on behalf of Investigators DART AD (2008). A randomised, blinded, placebo-controlled trial in dementia patients continuing or stopping neuroleptics (the DART-AD trial). *Public Library of Science Medicine, 5*(4):e76. doi:10.1371/journal.pmed.0050076

Ballard, C., Day, S., Sharp, S., Wing, G. & Sorensen, S. (2008). Neuropsychiatric symptoms in dementia: importance and treatment considerations. *International Review of Psychiatry, 20*, 396–404.

Ballard, C., Khan, Z., Clack, H. & Corbett, A. (2011). Nonpharmacological treatment of Alzheimer disease. *Canadian Journal of Psychiatry, 56*(10), 589–595.

Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. London: Institute of Psychiatry, King's College London.

Banerjee, S., Willis R., Matthews, D., Matthews, D., Contell, F., Chan, J. & Murray, J. (2007). Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry, 22*(8), 782–88. doi: 10.1002/gps.1741.

Bird, M. & Moniz-Cook, E. (2008). Challenging behaviour in dementia; a psychosocial approach to intervention. In B. Woods & L. Clare (Eds.), Handbook of the clinical psychology of ageing, p.571–594. Chichester: Wiley.

British Psychology Society (2011). *Good Practice guidelines on the use of psychological formulation.* Leicester: Author.

Brooker, D. (2005). Dementia care mapping: a review of the research literature. *The Gerontologist, 45* (Special Issue 1), pp.11–18.

Chenoweth, L., King, M.T., Jeon, Y.H., Brodaty, H., Stein-Parbur, J., Norman, R.M., Haas, M. & Luscombe, G. (2009). Caring for aged dementia care resident sudy (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology, 8*, 317–25.

Cohen-Mansfield, J. (2000). Nonpharmacological management of behavioural problems in persons with dementia: The TREA model. *Alzheimer Care Quarterly 1*, 22–34.

Cohen-Mansfield, J., Libin, A. & Marx, M.S. (2007). Nonpharmacological treatment of agitation: A controlled trial of systematic individualized intervention. *Journals of Gerontology. Series A Biological Sciences and Medical Sciences, 62*, 908–16.

Committee on the Safety of Medicines (2004). *Atypical antipsychotic drugs and stroke: Message from Gordon Duff, Chairman, Committee on Safety of Medicine*s (CEM/CMO/ 2004/1). Medicines and Healthcare Products Regulatory Agency.

Department of Health (2009). *Living well with dementia – the national dementia strategy.* Department of Health: London.

Department of Health, Social Services and Public Safety in Northern Ireland (2011). *Improving services in Northern Ireland. A regional strategy.* DHSSPSNI: Belfast. http://www.dhsspsni.gov.uk/show_publications?txtid=53089.

Dexter-Smith, S. (2010). Integrating psychological formulations into older people's services – three years on (Part 1). *PSIGE Newsletter, 112*, 8-11.

Division of Clinical Psychology (2007). *Marketing strategy for clinical psychologists.* Retrieved from dcp.bps.org.uk/document-download-area/document-download$.cfm?file_uuid=AC0686B5-1143-DFD0-7E06-1EA51AB27AEA&ext=pdf.

Douglas, S., James, I. & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment, 10*, 171179. doi: 10.1192/apt.10.3.171.

Eggermont, L.H.P. & Scherder, E.J.A. (2005). Physical activity and behaviour in dementia: A review of the literature and implications for psychosocial intervention in primary care. *Dementia, 5*(3), 411–428. doi:10.1177/1471301206067115.

Eggenberger, E., Heimerl, K. & Bennett, M., (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content and didactic methods in different care settings. *International Psychgeriatrics, 25*(3), 345–58.

European Union Social Protection and Social Inclusion Unit (2009). *Discussion paper: Coping with Alzheimer's and other related diseases – improving patient care at home: How to cope (non-pharmacologically) with crisis situations (behavioural disorders) occurring in patients' home.* Retrieved from http://www.peer-review-social-inclusion.eu/peer-reviews/2009/alzheimers-and-related-diseases/pr-fr-2009-discussion-paper/download.

Finkel, S., Silva, J.C., Cohen, G., Miller, S. & Sartorius, N. (1997). Behavioral and psychological signs and symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *International Psychogeriatrics, 8*, 497–500.

Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R. & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *British Medical Journal, 332*(7544), 756–61. doi:10.1136/bmj.38782.575868.7C.

Fossey, J. & James, I.A., (2008). *Evidence-based approaches for improving dementia care in care homes.* London: Alzheimer's Society.

Health Foundation (2011). *Learning report: Making care safer.* London: The Health Foundation.

Hussain, R.A. & Brown, D.C. (1987). Use of two-dimensional grid patterns to limit hazardous ambulation in demented patients. *Journal of Gerontology, 42*, 558–560.

James, I.A. (2011). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment.* London: Jessica Kingsley.

James, I.A., Mackenzie, L., Pakrasi, S. & Fossey, J. (2008). Non-pharmacological treatments of challenging behaviour. *Nursing and Residential Care, 10*(5), 228–232.

Johnstone, L. & Dallos, R. (2006). Introduction to formulation. In L. Johnstone & R. Dallos (Eds.), *Formulation in psychology and psychotherapy: Making sense of people's problems* (pp.1–16). London, New York: Routledge.

Kitwood, T. (1997). *Dementia reconsidered.* Buckingham: Open University Press.

Kunik, M., Martinez, M., Snow, A. et al. (2003). Determinants of behavioural symptoms in dementia patients. *Clinical Gerontology 26*(3), 83–89.

Lai, C.K.Y., Yeung, J.H.M., Mok, V. & Chi, I. (2009). Special care units for dementia individuals with behavioural problems. *Cochrane Database of Systematic Reviews, 4.* doi: 10.1002/14651858.CD006470.pub2.

Levy-Storms, L. (2008). Therapeutic communication training in long-term care institutions: Recommendations for future research. *Patient Education and Counseling 73*, 8–21.

Livingstone, G., Johnston, K., Katona, C., Paton, J. & Lyketsos, C. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry 162*(11), 1996–2021.

Márquez-González, M., Romero-Moreno, R. & Losada, A. (2010). Caregiving issues in a therapeutic context: New insights from the acceptance and commitment therapy approach. In N. Pachana, K. Laidlaw & R. Knight (Eds.), *Casebook of clinical geropsychology: International perspectives on practice*, pp.33–53). New York: Oxford. University Press.

Marriott, A., Donaldson, C., Tarrier, N. & Burns, A. (2000). The effectiveness of cognitive behavioural family intervention in reducing the burden of care in carers of patients of Alzheimer's disease. *British Journal of Psychiatry, 176*, 557–562.

Moniz Cook, E.D., De Vugt, M., Verhey, F., James, I. (2008). Functional analysis-based interventions for challenging behaviour in dementia. (Protocol). *Cochrane Database of Systematic Reviews, 1.* doi: 10.1002/14651858.CD006929.

Moniz-Cook, E., Swift K., James, I., Malouf, R., De Vugt, M. & Verhey, F. (2012). Function analysis-based interventions for challenging behaviour in dementia. *Cochrane Library*, 2. Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006929.pub2/abstract;jsessionid=C8458739 A4EC3A21257500EE5D388DED.d04t01

Moniz-Cook, E., Woods, R. & Richards, K. (2001a). Functional analysis of challenging behaviour in dementia: The role of superstition. *International Journal of Geriatric Psychiatry, 16*, 45–56.

Moniz-Cook, E., Woods, R., Gardiner, E., Silver, M. & Agar, S. (2001b). The Challenging Behaviour Scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. *British Journal of Clinical Psychology, 40*(3), 309–322.

Namazi, K.H., Rosner, T.T. & Calkins, M.P. (1989). Visual barriers to prevent ambulatory Alzheimer's patients from exiting through an emergency door. *The Gerontologist, 29*, 699–702.

NHS Institute for Innovation and Improvement. (2011). *An economic evaluation of alternative to anti psychotic drugs for individuals living with dementia.* Matrix Evidence. Coventry: NHS Institute for Innovation and Improvement.

NHS Wales. (2011). *National dementia vision for Wales. Dementia supportive communities.* Retrieved from http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf.

NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care. Clinical Guideline 42.* National Institute for Health and Clinical Excellence & the Social Care Institute for Excellence.

NICE (March 2011). *Dementia Supporting people with dementia and their carers in health and social care.* Retrieved from www.nice.org.uk/nicemedia/live/10998/30317/30317.pdf.

Olazaran J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., del Ser T., Woods, B., Beck, C., Auer, S., Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J.M., Collins, H., Teri, L., Mittelman, M., Orrell, M., Feldman, H.H. & Muniz, R., (2010). Non-pharmacological therapies in Alzheimer's Disease: A systematic review of efficacy, *Dementia and Geriatric Cognitive Disorders, 30*, 161–178.

Onyett, S. (2007). *Working psychologically in teams.* Leicester: The British Psychological Society.

Opie, J., Rosewarne, R. & O'Connor, D.W. (1999). The efficacy of psychosocial approaches to behaviour disorders in dementia: a systematic literature review. *Australian and New Zealand Journal of Psychiatry, 33*, 789–799.

Pointon, B. (2001). Whose service is it? A pressing need for change. *Journal of Dementia Care, 9*(5), p.23-25.

Robert, P.H., Verhey, F.R., Byrne, E.J. et al. (2005) Grouping for behavioral and psychological symptoms in dementia: clinical and biological aspects. Consensus paper of the European Alzheimer disease consortium. *European Psychiatry, 20*, 490–496.

Robinson, L., Hutchings, D., Dickinson, H.O., Corner, L., Beyer, F., Finch, T., Hughes, J., Vanoli, A., Ballard, C. & Bond, J. (2007). Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: A systematic review. *International Journal of Geriatric Psychiatry. 22*(1), 9–22. DOI: 10.1002/gps.1643.

Royal College of Nursing (2011). Dignity in dementia: transforming general hospital care: findings from survey of professional. Royal college of Nursing.

Royal College of Psychiatrists (2010). *A competency-based curriculum for specialist core training in psychiatry.* Retrieved from: www.rcpsych.ac.uk/training/curriculum2010.aspx.

Royal College of Psychiatrists (2011). *Report of the National Audit of Dementia Care in General Hospitals*. Editors: J. Young, C. Hood, R. Woolley, A. Gandesha & R. Souza. London: Healthcare Quality Improvement Partnership.

Royal College of Psychiatrists (2005). *Atypical antipsychotics and behavioural and psychiatric symptoms of dementia. royal college of psychiatrists*. Retrieved from http://www.rcpsych.ac.uk/PDF/BPSD.pdf.

Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007). *Challenging behaviour: a unified approach Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices college report CR 144*. Retrieved from http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf.

Schneider, L.S., Tariot, P.N., Dagerman, K.S., Davies, S.M., Hsiao, J.K., Ismail, M.S., Lebowitz, B.D., Lyketsos, C.G., Ryan, J.M., Stroup, T.S., Sultaer, D.L., Weintraub, D. & Lieberman, J.A. (2006). Effectiveness of atypical antipsychotic drugs in patients with Alzheimer's disease. *New England Journal of Medicine, 355*, 1525–1538.

Schneider, L., Dagerman, K. & Insel, P. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomised placebo-controlled trials. *Journal of American Medical Association, 294*, 1934–1943.

Stokes G. (2000). *Challenging behaviour in dementia: A person centred approach*. Bicester: Winslow Press.

Scottish Government (2010). *Scotland's national dementia strategy*. Retrieved from www.scotland.gov.uk/Publications/2010/09/10151751/0. Edinburgh: Scottish Government.

Teri, L., Logsdon, R.G., McCurry, S.M. (2008). Exercise interventions for dementia and cognitive impairment: The Seattle Protocols. *Journal of Nutrition, Health and Aging, 12*, 391–394.

Vink, A.C., Bruinsma, M.S. & Scholten, R.J.P.M. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews, 4*. doi: 10.1002/14651858.CD003477.pub2.

Volicer, L. & Hurley, A. (2003). Management of behavioural symptoms in progressive degenerative dementias. *Journal of Gerontology, 58A* (9), 837–845.

Welsh Assembly Government (2011). *National dementia vision for Wales*. http://wales.gov.uk/topics/health/publications/health/guidance/dementia/?lang=en

Wood-Mitchell, A., James, I.A., Waterworth, A., Swann, A. & Ballard, C. (2008). Factors influencing the prescribing of medications by old age psychiatrists for behavioural and psychological symptoms of dementia: a qualitative study. *Age and Ageing, 37*(5), 547–52.

Woods, B. & Moniz-Cook, E. (2012). Pain relief – a first-line response to agitation in dementia? *Nature Review Neurology, 8*, 7–8.

Woods, B., Spector, A.E., Jones, C.A., Orrell, M., Davies, S.P. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews, 2*. doi:10.1002/14651858.CD001120.pub2.

Woods, B., Spector, A., Prendergast, L. & Orrell, M. (2005a). Cognitive stimulation to improve cognitive functioning in people with dementia'. *Cochrane Database of Systematic Reviews, Issue 4*. Chichester: John Wiley.

Woods, B., Spector, A., Jones, C., Orrell, M. & Davies., S. (2005b). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews, Issue 2*. Chichester: John Wiley.

Appendix 1: Behaviour monitoring chart

Behaviour Chart for ……

Behaviour displayed ……

Please record any episodes of the above behaviour (day/night)
Aim – to record the frequency and the circumstances of the incident

Date & Time	What was the person doing just before the incident?
Where did the incident occur?	What did you see happen? (actual behaviour)
Which staff were involved (initials)	What did the person say at the time of the incident?
Possible reason for the behaviour?	

How did the person appear at the time of the incident? (tick all that apply)

Angry	☐	Happy	☐
Anxious	☐	Irritable	☐
Bored	☐	Physically unwell	☐
Content	☐	Restless	☐
Depressed	☐	Sad	☐
Despairing	☐	Worried	☐
Frightened	☐	Other (please state):	☐
Frustrated	☐		

How was the situation resolved?

Tees, Esk and Wear Valleys NHS

NHS Foundation Trust

Care Home Liaison Behaviour Chart

What is a behaviour chart?
A behaviour chart is a chart to recognise challenging behaviours. An example of a chart already filled out is shown to the right of this page.

What information does a behaviour chart give you?
A behaviour chart gives us a really detailed picture of challenging behaviours. It shows us how often the behaviour is happening and what is happening at the time of the behaviour.

Who should fill out the behaviour charts?
The behaviour charts need to be filled out by the staff member who witnesses the behaviour following discussion with senior staff on duty.

Do I fill out a chart for every time the behaviour occurs?
Yes please. We need to know how much of a problem it is (e.g. how often it happens). If you do not record it each time we can miss important information. In addition if we don't get completed charts it will lead us to think that there is no problem.

How long will we have to complete the behaviour charts for?
It will usually be between 3-8 days, or approximately 20 completed charts.

Behaviour Chart for……Harry……..

Behaviour displayed ……Hitting out……

Please record any episodes of the above behaviour (day/night)
Aim – to record the frequency and the circumstances of the incident

Date & Time **28/01/2007 1pm**	What was the person doing just before the incident? **In their room being assisted to change after being incontinent.**
Where did the incident occur? **bedroom**	What did you see happen? (actual behaviour) **Harry started shouting and was hitting out at staff with a closed fist. He hit staff on the arm 3 times causing a red mark.**
Which staff were involved (initials) **SW, AN**	What did the person say at the time of the incident? **"get off me", "I don't want your help"**
Possible reason for the behaviour? **Didn't want staff to help with getting him changed. Embarrassed by people undressing him.**	

How did the person appear at the time of the incident? (tick all that apply)

Angry	✓	Happy	☐
Anxious	☐	Irritable	☐
Bored	☐	Physically unwell	☐
Content	☐	Restless	☐
Depressed	☐	Sad	☐
Despairing	☐	Worried	☐
Frightened	☐	Other (please state):	☐
Frustrated	✓		

How was the situation resolved?
Staff kept trying to reassure Harry and carried on with the care intervention. As soon as staff had finished he stopped being aggressive.

THE CHALLENGING BEHAVIOUR SCALE (CBS) FOR OLDER PEOPLE LIVING IN CARE HOMES

Name ……

Age ……. Sex … M / F Diagnosis of Dementia … Y / N / Don`t know

Residence …… Date ……

Checklist Completed By ……

PHYSICAL ABILITY (delete as applicable)

1. Able to walk unaided / Able to walk with aid of walking frame / In a wheelchair
2. Continent / Incontinent of urine / Incontinent of faeces / Incontinent of urine + faeces
3. Able to get in or out of bed/chair unaided / needs help to get in or out of bed/chair
4. Able to wash and dress unaided / needs help to wash and dress
5. Able to eat and drink unaided / needs help to eat and drink

Over the page is a list of challenging behaviours that can be shown by older adults in residential or nursing settings.
For each behaviour listed consider the person over past 8 weeks and mark:

INCIDENCE: Yes / Never. If Yes move to Frequency

FREQUENCY:
4: This person displays this behaviour **daily or more**
3: This person displays this behaviour **several times a week**
2: This person displays this behaviour **several times a month**
1: This person displays this behaviour **occasionally**

DIFFICULTY:
Then *for each behaviour shown* mark down how difficult that behaviour is to cope with, when that person shows it, according to the following scale:

4: This causes a lot of problems
3: This causes quite a lot of problems
2: This is a bit of a problem
1: This is not a problem

N.B. If a person does not show a behaviour no frequency or difficulty score is needed.
If the person causes a range of difficulty with anyone behaviour, mark down the score for the worst it has been over the last few (eight) weeks.

	CHALLENGING BEHAVIOUR	INCIDENCE		FREQUENCY		DIFFICULTY		CHALLENGE	
		Yes	Never	1=occasionally 2=several/month 3=several/week 4=daily or more		1=no problem 2=bit of problem 3=quite a lot of problems 4=lots of problems		Frequency x Difficulty	
1	**Physical Aggression** (hits, kicks, scratches, grabbing, etc.)								
2	**Verbal Aggression** (insults, swearing, threats, etc.)								
3	**Self Harm** (cuts/hits self, refuses food/starves self, etc.)								
4	**Shouting**								
5	**Screaming/Crying out**								
6	**Perseveration** (constantly repeating speech or actions, repetitive questioning or singing)								
7	**Wandering** (walks aimlessly around home)								
8	**Restlessness** (fidgets, unable to settled down, pacing, `on the go`, etc.)								
9	**Lack of motivation** (difficult to engage, shows no interest in activities, apathy, etc.)								
10	**Clinging** (follows/holds on to other residents/staff, etc.)								
11	**Interfering with other people**								
12	**Pilfering or Hoarding** (possessions, rubbish, paper, food, etc.)								
13	**Suspiciousness** (accusing others, etc.)								
14	**Manipulative** (takes advantage of others, staff, etc.)								
15	**Lack of Self Care** (hygiene problems, dishevelled, etc.)								
16	**Spitting**								
17	**Faecal Smearing**								
18	**Inappropriate Urinating** (in public, not in toilet, etc.)								
19	**Stripping** (removes clothes inappropriately, flashes, etc.)								
20	**Inappropriate Sexual Behaviour** (masturbates in public, makes inappropriate `advances` to others, etc.)								
21	**Sleep Problems** (waking in night, insomnia, etc.)								
22	**Non-compliance** (deliberately ignores staff requests, refuses food, resists self care help, etc.)								
23	**Dangerous Behaviour** (causes fires or floods, etc.)								
24	**Demands Attention**								
25	**Lack of Occupation** (sits around doing nothing, etc.)								
	TOTALS **Add scores (1 – 25) for each column**		**25**		**100**		**100**		**400**

STAFF `PROMPT` SHEET

HOW OFTEN DOES THE PROBLEM / BEHAVIOUR OCCUR?

4: This person displays this behaviour **daily or more**
3: This person displays this behaviour **several times a week**
2: This person displays this behaviour **several times a month**
1: This person displays this behaviour **occasionally**
0: This behaviour is **never** displayed by this person

HOW MUCH OF A PROBLEM IS THIS BEHAVIOUR?

4: This causes **a lot** of problems
3: This causes **quite a lot** of problems
2: This causes **a bit** of a problem
1: This is **not** a problem

WE ARE INTERESTED IN THE WORST THE RESIDENT HAS BEEN OVER THE LAST TWO MONTHS.

If a person does not show a behaviour no difficulty (or problem) score is needed.
If the person causes a range of difficulty with any one behaviour, mark down the score for the worst is has been over the last few weeks.

Instructions for use of the Challenging Behaviour Scale

Background

1. This scale was initially derived as the Problem Behaviour Checklist (Inventory) and used in a staff training study.
   Reference: Moniz-Cook, E.D., Agar, S., Silver, M., Woods, R.T., Wang, M., Elston, C. and Win, T. (1998) `Can Staff Training Reduce Behavioural Problems in Residential Care for the Elderly Mentally Ill?` *International Journal of Geriatric Psychiatry*, 13, p.149-158.

2. On the basis of initial reliability and validity studies it was changed and re-labelled – The Challenging Behaviour Scale (CBS).

3. Reliability and validity studies were carried out in Continuing Care Hospitals and residential and nursing homes. Although you can use the scale for non-demented institutional populations its global properties will be of little use. For example people with a depressive illness may present with self harm whereas this is not often seen in dementia.

4. This scale was developed on the basis of staff report : hence eating problems do not feature strongly and were included under the `non-compliant` category. You may wish to add some items of eating problems for your own use but the norms will have to be adjusted.

5. This is a global scale and although it has been subject to factor analysis, other scales for aggression, agitation and eating problems are more useful for specific behaviours. This scale does have a category for `apathy` / depression / doing nothing which may be of use in monitoring.

6. The Incidence and Frequency ratings are useful in measuring `actual behaviour` if guidelines are followed (see later). The Difficulty and Challenging scores are more measures of staff coping / management / perception. The Difficulty domain is only required to calculate Challenge scores whilst the Challenge score is a measure of management difficulty or coping.

Contract

1. I would be grateful if you would supply me with information of use of this scale, (i.e. if you decide to use it and how). I wish to develop it further and keep a database of it`s use.

2. Please do not circulate the Scale and Staff Prompt Sheet without my permission, as I am currently negotiating detail publication with a test agency.

3. Please refer to Moniz-Cook, E.D., Woods, R.T., Gardiner, E., Silver, M. & Agar, S (2001) `The Challenging Behaviour Scale (CBS): Development of a Scale for Staff Caring for Older People in Residential and Nursing Homes`. *British Journal of Clinical Psychology. 40 (3): 309-322* for detail of development, reliability and validity. Please turn over for specific instructions.

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CHALLENGING BEHAVIOUR SCALE INSTRUCTIONS

1. Use as a structured interview with at least 2 members of staff (one qualified and one unqualified), for individual clinical work or for `research` work / monitoring.
2. If you hand these out then make sure that one person who knows the person well (key worker), a qualified member of staff and one other do the checklist in a group.
3. If a staff member is stressed out this may influence the results (especially on some items and the Difficulty and Challenge rating).
4. Repeat testing is best done with the same staff group, but reliability is not bad if group is different as long as it is a group and not one person.
5. You need to wait approximately 8 weeks before you repeat testing because of wording of frequency items.

Scoring

1. Multiply each Frequency x Difficulty item to get a Challenge item score.
2. Add Challenge score to make total Challenge (do not add Frequency, add Difficulty and then multiply for Challenge).
   By this method the maximum Challenge score is 400.
3. If you want to measure the (more reliable) actual behaviour use total Incidence and total Frequency on their own.

Notes

1. The Incidence and Frequency domain are fairly stable measures of actual behaviour. The Difficulty domain is not often used on its own but is used to calculate the Challenge domain, which is a measure of staff coping / management. This latter domain (Challenge) is very sensitive and is only reliable if you follow the rules.
2. It is useful in assessing behaviour in whole environments, e.g. a ward – ask the person in charge to complete with at least the key worker and one other.
3. Measurement of individual cases – use as a structured interview with the same pair of staff pre and post / at least one staff member of the baseline pair.

References for CBS

Moniz-Cook, E.D., Agar, S., Silver, M., Woods, R.T., Wang, M., Elston, C & Win, T. (1998) `Can Staff Training Reduce Behavioural Problems in Residential Care for the Elderly Mentally Ill? `, *International Journal of Geriatric Psychiatry*, **13**, 149-158.

Moniz-Cook, E.D. (1998) `Psychosocial Approaches To Challenging Behaviour In Care Settings – A Review`. *Journal of f Dementia Care*, **6** (5), .33-38.

Silver, M., Moniz-Cook, E.D & Wang, M. (1998) `Stress And Coping With Challenging Behaviour In Residential Settings For Older People` Mental *Health Care*, **2** (4), 128-131.

Moniz-Cook, E.D., Gardiner, E. & Woods, R.T. (2000) `Staff Factors Associated with the Perception of Behaviour as `Challenging` in Residential and Nursing Homes`. *Aging and Mental Health*, **4**(1), 48-55.

Cole R.P., Scott, S. & Skelton-Robinson, M. (2000) `The effect of Challenging Behaviour and Staff Support on the Psychological Wellbeing of Staff Working with Older Adults. *Aging and Mental Health,* **4** (4) .359-365.

Moniz-Cook, E.D Woods, R.T. & Richards, K. (2001) `Functional Analysis of Challenging Behaviour in Dementia: The Role of Superstition`. *International Journal of Geriatric Psychiatry*, **16**, p.45-56.

Moniz-Cook, E.D., Woods, R.T., Gardiner, E., Silver, M. & Agar, S (2001) `The Challenging Behaviour Scale (CBS): Development of a Scale for Staff Caring for Older People in Residential and Nursing Homes`. *British Journal of Clinical Psychology.* **40** (3).309-322.

Moniz-Cook, E.D Stokes, G. & Agar, S. (2003) `Difficult Behaviour and Dementia in Nursing Homes: Five Cases of Psychosocial Intervention`. *International Journal Clinical Psychology and Psychotherapy*, 10, 3, 197-208

Freeman - Asthill, L. (2004) `Staff training and challenging behaviour in a day hospital. ` Dementia **3** (3), 384-392

Lam, C.L. Chan, W.C. Cycbie, C.M. Mok, S.W. Li. & Linda C.W. Lam. (2006) `Validation of the Chinese Challenging Behaviour Scale: clinical correlates of challenging behaviours in nursing home residents with dementia`. *International Journal of Geriatric Psychiatry* **21** 792-799

Hoe, J. Hancock, G. Livingston, G. & Orrell, M. (2006) Quality of Life of people with dementia in residential care homes *British Journal of Psychiatry* **188**, 460-464

Orrell, M., Hancock, G.,Hoe, J., Woods B., Livingston, G. & Challis, D. (2007) A cluster randomised controlled trail to reduce the unmet needs of people with dementia living in residential care *International Journal of Geriatric Psychiatry* **22** 1127- 1134

Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, de Vugt M, Mountain G, O'Connell M, Harrison J, Vasse E, Dröes RM, & Orrell M For the INTERDEM group. (2008) A European consensus on outcome measures for psychosocial intervention research in dementia care *Aging & Mental Health* 1**2** ,1, 14- 25

Moniz-Cook E D (2010) National Institute of Health Research (NIHR) Research : Living well with dementia in care homes Alzheimers Society Newsletter **97** (April), 6-7

Moniz-Cook (2010) Psychosocial Interventions for 'living well' in care homes *Alzheimers Society Research ejournal* Issue **11**, pp 12 – 15

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INF207/04.2013

Health, Social Care and Sport Committee

Thursday 21 September 2017

Item 8 – Inquiry into the use of antipsychotic medication in care homes – evidence session 5

Notes of session with an individual affected by the issue. This is a summary of what the individual told the Committee.

- The Committee heard from an individual whose mother had been prescribed anti-psychotic medication after a diagnosis of dementia.
- Her mother was admitted to hospital following a house fire, and this led to a diagnosis of dementia to finally be confirmed.
- The daughter told us that from the family had to deal with problems with inexperienced care home staff from the outset. Her mother was placed in three care homes overall.
- As a result of dementia, her mother was verbally challenging, but there appeared to be no attempt to understand what was causing the aggression until the Community Psychiatric Nurse (CPN) became involved.
- Quetiapine, Lorazepam and Diazepam were all prescribed by CPN in the first care home.
- Initially CPN came once a month to perform medication reviews, but that stopped when the CPN went on sick leave. No replacement put in place.
- Her mother gained over two stone in weight, partly because the medication is stated as stimulating appetite and a sweet tooth. In addition, her mother was not offered any exercise.
- Due to increased weight and being immobile due to effect of drugs a fall led to the mother being re-admitted to hospital for treatment of a broken hip. During that stay in hospital, and because of the challenging behaviour, the witness's mother was restrained on occasion and regularly given sedating medication Lorazepam and Diazepam.
- The mother was transferred to the older people's unit in the local Psychiatric Hospital for assessment. Further medication given. Quetiapine stopped and Trazadone given plus other 'calming' medicines.
- After being moved to another care home, the witness was told after just seven days that they couldn't cope with her mother and she had to leave. Following an intervention by the family, this did not happen and a key worker and social worker were assigned.

- Despite having a good relationship with the key worker, he left after two months because he didn't like the approach being taken and what he was being asked to do.
- Increased Trazodone was prescribed to the mother, and it did settle her symptoms.
- For the final 18 months of the witnesses' mother's life she couldn't speak. She was overwhelmed by a 'huge chemical cosh', which was prescribed and administered on the advice of professionals.
- When the palliative care team became involved towards the end of her mother's life they withdrew all medication. For the last 3-4 days of the mother's life she was lucid enough on occasion to talk to her family.
- The witness suggested a number of recommendations:
    - Staff training – including dementia specific skills – is essential and needed;
    - The prescribing of antipsychotic medication shouldn't be the default position;
    - Professional clinical staff need to talk to the family more and involve them in the decision-making.

Mae cyfyngiadau ar y ddogfen hon