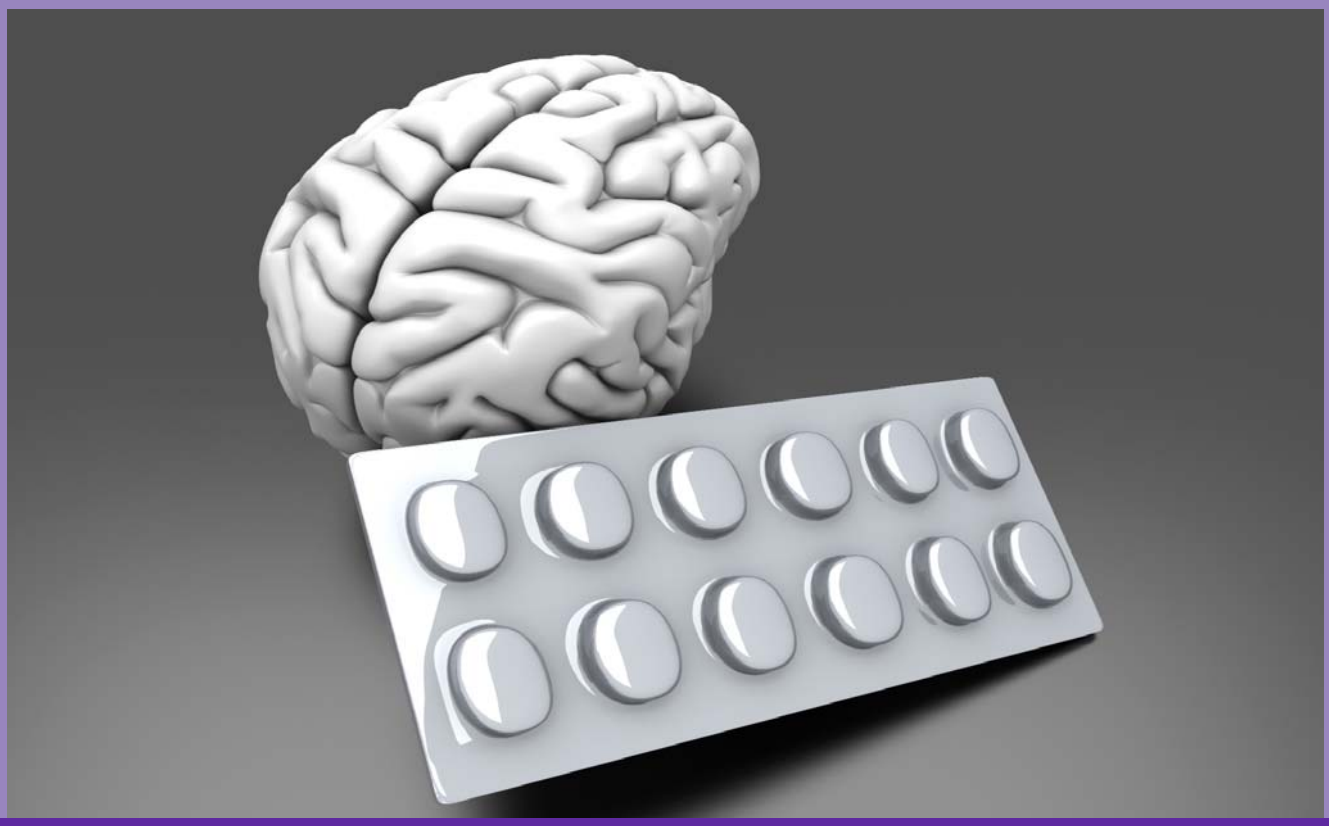
The British Psychological Society

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



September 2012

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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 750, 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 delusions, hallucinations, anxiety, apathy, agitation, aggression, wandering and disinhibition (Ballard et al., 2001) 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.

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; Fossey et al., 2006). 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. 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).

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.

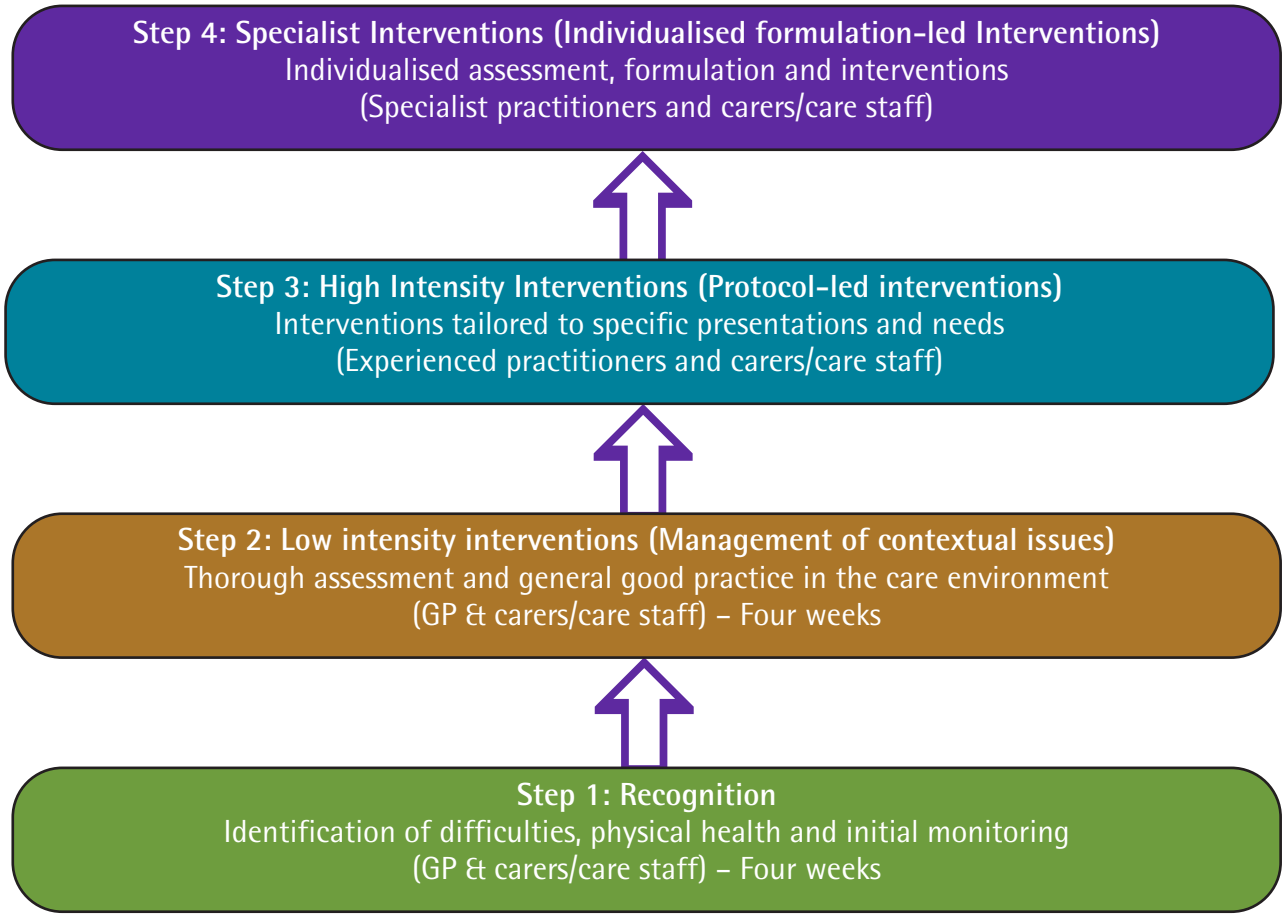


Figure 1: The stepped care model

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.

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).

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).
- **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, Kuniks et al., Volicer and Hurley, 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) 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.).
- 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).
- **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).
- **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.

Summary

1. The majority of people living with dementia are likely to experience behavioural and psychological difficulties at some point during their illness.
2. 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.
3. 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.
4. 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.
5. 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.
6. 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).
7. 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.
8. 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.
9. 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.

10. 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).

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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?

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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.

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	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 problem 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**

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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.

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