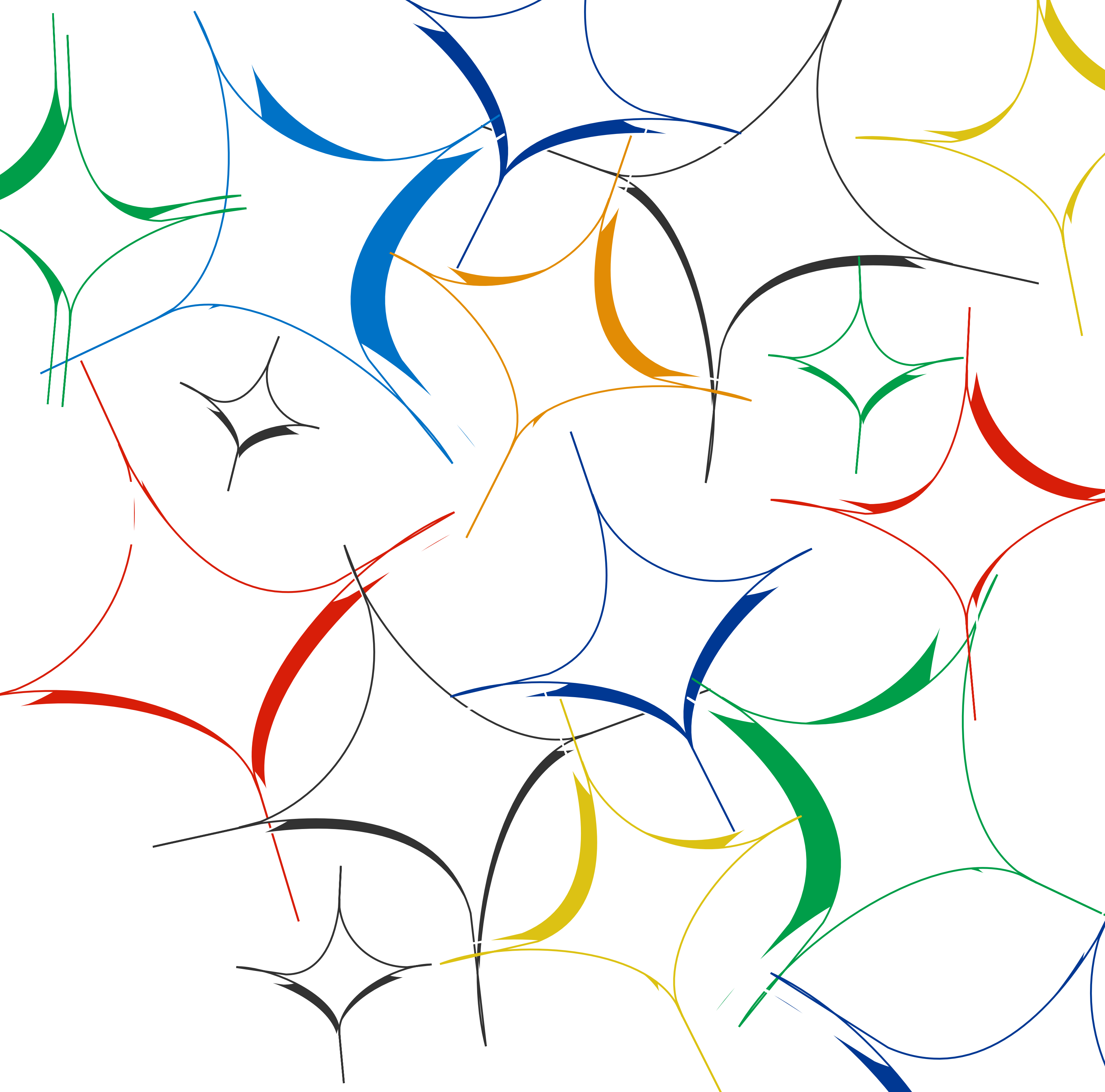


Reducing Antipsychotic Prescribing in Dementia Toolkit

Based on version 4 of a document produced by Sussex Partnership NHS Foundation Trust

Adapted for PrescQIPP by Cherise Howson, Primary Care Pharmacist

NHS
PrescQIPP

Contents

1 A BASIC INTRODUCTION TO NON – PHARMACOLOGICAL APPROACHES TO MANAGE BPSD AND SUPPORTING TOOLS

2 GUIDANCE AND SUPPORTING TOOLS FOR GPS ON REVIEWING AND STOPPING ANTIPSYCHOTICS IN PEOPLE LIVING WITH DEMENTIA

Key recommendations

- Antipsychotics appear to have a limited positive effect in treating behavioural and psychological symptoms of dementia (BPSD) and can cause significant harm to people with dementia.
- Use of antipsychotics in people with dementia can worsen cognition, increase the risk of falls and increase the risk of stroke and death.
- All patients with dementia currently on antipsychotics for behavioural problems who have not had a trial discontinuation in the last 3 months should have the antipsychotic reviewed and stopped to assess the risks and benefits of continued treatment. There are limited circumstances when antipsychotics are justified beyond 3 months and a plan for discontinuation should be attempted. Withdrawal of higher dose antipsychotics should take place slowly over a period of 2-4 weeks unless there are specific and distressing side effects from medication.
- It is recommended that non-pharmacological approaches (therapy that does not involve medication) are used as a first line approach.[3] Pharmacological intervention should only be offered in the first instance if a person is severely distressed or there is an immediate risk of harm to the person or others.

This pack also provides patient and carer information on managing patients with dementia.

Adaptable documents to accompany this toolkit (Attachments 1-14) are available on the PrescQIPP website:

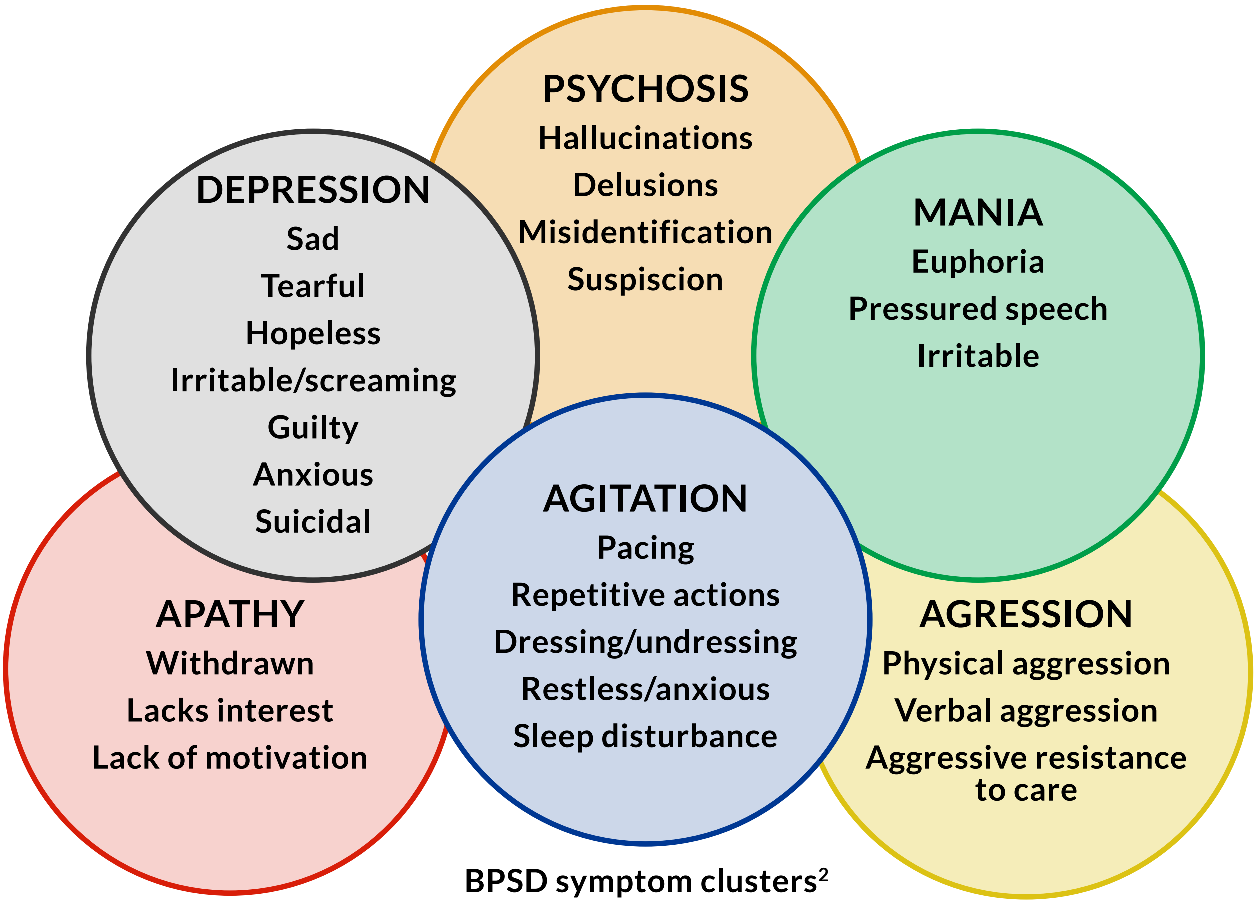
http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Introduction

What is BPSD?

Behavioural and Psychological Symptoms of Dementia (BPSD) refers to a group of symptoms of disturbed perception, thought content, mood or behaviour, frequently occurring in patients with dementia.[1]

- Challenging non-cognitive symptoms — include hallucinations, delusions, anxiety, and marked agitation.
- Challenging behaviour — includes aggression, agitation, wandering, hoarding, sexual disinhibition, apathy, and disruptive vocal activity (such as shouting).
- Challenging behaviour is often an active attempt by the person with dementia to meet or express a physical or psychological need. For example, agitation may be communicating boredom, anxiety, embarrassment or be a response to pain or discomfort or an environmental challenge, e.g. noise.



BPSD symptom clusters[2]

More than 90% of people with dementia will experience BPSD as part of their illness and nearly two thirds of people with dementia living in care homes are experiencing symptoms at any one time.[3]

Non–pharmacological approaches to manage BPSD

It is recommended that non-pharmacological approaches (therapy that does not involve medication) are used as a first line approach.[3] Pharmacological intervention should only be offered in the first instance if a person is severely distressed or there is an immediate risk of harm to the person or others.[4]

Approaches can include:

- Aromatherapy
- Multisensory stimulation
- Animal assisted therapy
- Therapeutic use of music and or dancing
- Massage

Outlined later in this document is a list of some typical causes for distress and challenging behaviours along with some practical advice.

The problem with using antipsychotics

- There is an increased risk of cerebrovascular adverse events (CVAEs) and a small increased risk of death in patients prescribed antipsychotics for treatment of BPSD. It is likely that ALL antipsychotic drugs are associated with an increased risk of stroke.
- A Department of Health report in 2009[5] assumed that annually approximately 180,000 people with dementia are given antipsychotic medication. Assuming use for an average treatment episode of 6–12 weeks, this equates to:
  - An additional 1,800 deaths per year; and
  - An additional 1,620 CVAEs, around half of which may be severe.
- Antipsychotic drugs can also cause sedation, increase the risk of falls, and long-term use can accelerate cognitive decline.
- People with dementia who develop non–cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others.[4]
- People with dementia lewy body (DLB) with mild to moderate non–cognitive symptoms should not be prescribed antipsychotic drugs, because those with DLB are at particular risk of severe adverse reactions, particularly neuroleptic sensitivity reactions such as the development of severe extrapyramidal features.
- Treatment with antipsychotics should be time limited and regularly reviewed every 3 months or according to clinical need.[4]

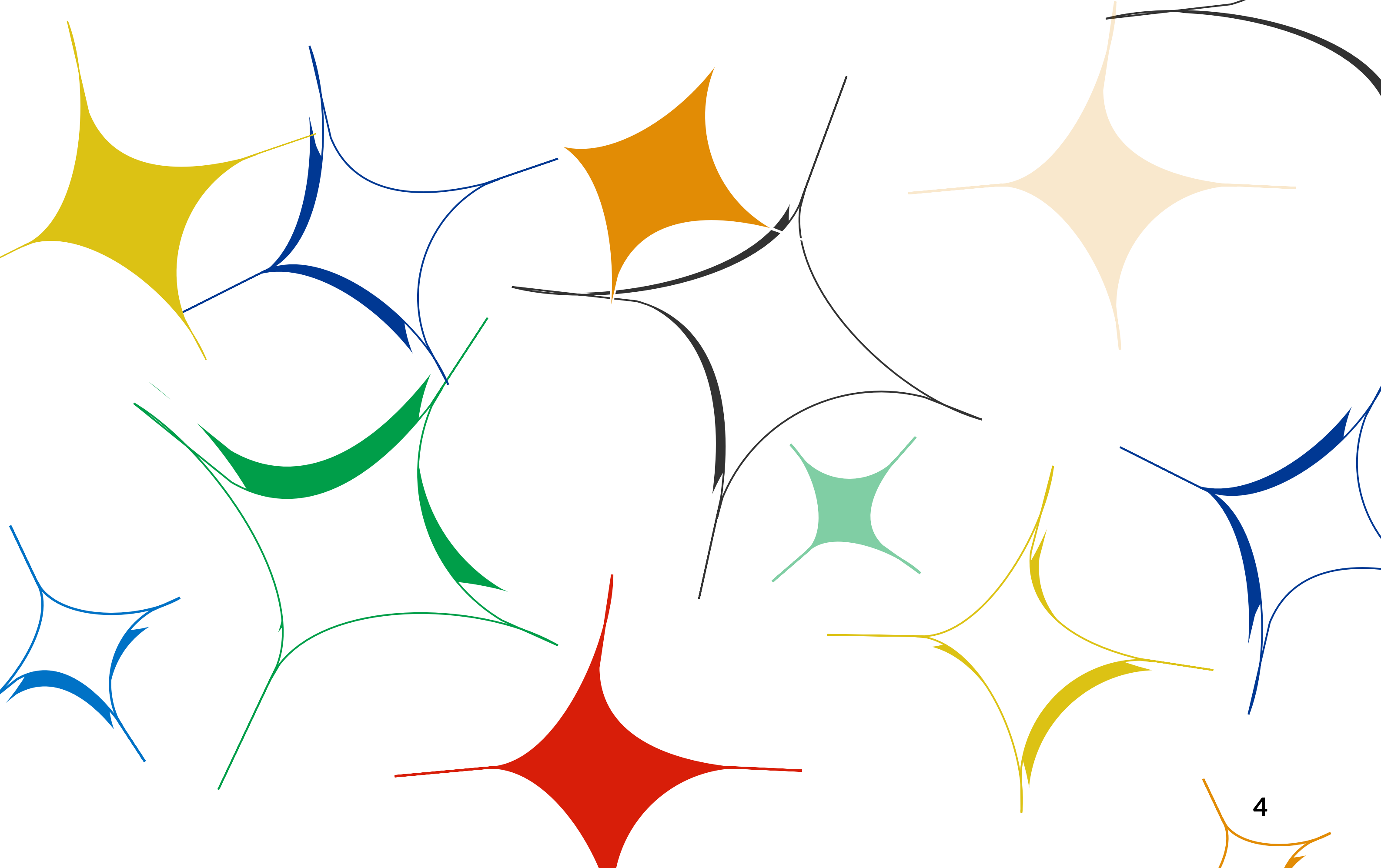
To assist in this process the resource pack includes:

- A basic introduction to behavioural approaches to minimise BPSD (p.4-10 and Attachment 1)
- A selection of pain assessment tools that can be used for people with dementia (p.11-16 and Attachments 2-4)
- An information sheet for carers/relatives (p.17 and Attachment 5)
- An information sheet for care home staff (p.17 and Attachment 6)
- The 'Good Sleep Guide' for people living with dementia: Information for Carers (p.xx and Attachment 7)
- Guidance on reviewing and stopping antipsychotics prescribed for BPSD (p.25 and Attachment 8)
- Two suggested audit tools (p.29-30 and Attachments 9&10)
- A form to record the decision to initiate an antipsychotic (p.31 and Attachment 11)
- A form to record that a review of re-prescribed antipsychotic has been done (p.34 and Attachment 12)
- A sample chart and blank chart for carers to use to keep a diary of behaviour, before and after stopping treatment (p.37 and Attachment 13)
- An example of an ABC chart for care home staff to use (p.39 and Attachment 14)
- A list of useful websites (p.42)

Summary of key points for managing patients with behavioural and psychological symptoms of dementia (BPSD)

An assessment and care-planning approach, which includes behavioural management, should be followed as soon as possible.

- If distress and or agitation are less severe, non–pharmacological interventions should be used before a pharmacological intervention is considered.
- Target symptoms should be identified, quantified and documented.
- Changes in target symptoms should be assessed and recorded at regular intervals.
- The effect of other co–morbidities, such as depression and anxiety, should be considered.
- If an antipsychotic is deemed necessary the choice of antipsychotic should be made after an individual risk versus benefit analysis.
- The dose should start low and then be slowly titrated.
- Treatment should be time limited and regularly reviewed, every 3 months or according to clinical need.
- If a patient on an antipsychotic for BPSD has not had a trial discontinuation in the last 3 months, they should have the antipsychotic reviewed and stopped to assess the risks and benefits of continued treatment unless:
    - » The antipsychotic was prescribed for a pre-existing condition prior to a diagnosis of dementia, e.g. bipolar disorder or psychotic depression.
    - » The patient is under regular review by a specialist for behavioural problems. This does not include reviews solely planned to assess the on-going benefits of prescribing cholinesterase inhibitors (e.g. donepezil) to delay cognitive decline.
    - » There is a detailed care plan in place for ongoing antipsychotic use.



SECTION 1

A basic introduction to non – pharmacological approaches to manage BPSD and supporting tools

1.1 Non-pharmacological approaches to challenging behaviour in people with dementia: A guide for GPs

It is recommended that non-pharmacological approaches are used as a first line approach.[3] Pharmacological intervention should only be offered in the first instance if a person is severely distressed or there is an immediate risk of harm to the person or others.[4]

What is meant by ‘challenging behaviour’?

Active attempt by the person with dementia to meet or express a physical or psychological need.

- For example, agitation may be communicating boredom, anxiety, embarrassment or be a response to pain or discomfort or an environmental challenge e.g. noise.
- Typical causes for distress and challenging behaviours are given in the left column in the following pages. Use the right column to offer suggestions to care home staff.
- These suggestions are recommended for staff with basic dementia awareness.
- Active involvement of relatives in a person’s care is linked to better outcomes.

If the difficulties are not resolved with these suggestions, either for an individual or the home, please refer to your local mental health services for specialist assessment and interventions.

Further advice can be sought from:

- Alzheimer’s Society website http://alzheimers.org.uk/
- Dementia UK – helpline for professionals for advice about individuals https://www.dementiauk.org/
- Social Care Institute for Excellence (SCIE) website – fact sheets, online training, training videos http://www.scie.org.uk/

An adaptable Word version of the following tables (Attachment 1) is available on the PrescQIPP website:
http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

POSSIBLE CAUSE: Physical health and medication side effects

Challenging behaviour may result from:	Ideas for staff:
Pain Resulting from numerous causes, e.g. joint, dental problems, discomfort from skin problems, constipation. **NB:** People with dementia are often not able to identify or may deny pain due to their cognitive impairment/communication difficulties. Pain is hugely undiagnosed.	• Use an appropriate tool to assess pain. • Observe pain response during personal care tasks and transfers.
Delirium People with dementia at higher risk. Requires medical diagnosis and treatment for underlying causes.	• GP review
Infections Urinary tract infection (UTI), thrush, chest, skin infections, cellulitis.	• GP review
Hunger, thirst and dehydration May be symptom of dementias (Alzheimer's, Lewy Body and Parkinson's-related dementia). Medication side effect.	• Check access to food and fluids. • Consider food and fluid chart. • Are they able to eat and drink, e.g. denture pain ulcers. • Consider involving speech and language therapy/dentist/dietitian.
Sleep disturbance	• Are they getting any exercise, sleeping too much during day, under stimulated? • Consider trying sleep hygiene, light therapy (seek advice from mental health staff).
Physical limitations For example - hearing, eyesight, bad feet/nails.	• Are staff ensuring they are clear enough, loud enough, not too loud, talking into the good ear or speaking slowly enough or approaching from the side where eyesight is best?
Medication side effects	• GP review

POSSIBLE CAUSE: Environmental factors

Challenging behaviour may result from:	**Ideas for staff:**
Under stimulation	• Use activities that are personally relevant to interests or previous work. Life story documents such as 'My Life Story' and 'This is me' are useful. • Provide 30 second plus spontaneous opportunities for conversations. • Social areas to encourage interactions.
Over stimulation	• May get agitated if too many people around, too noisy or after lunch if they are tired – consider quiet time, an afternoon nap, garden, sitting with calming music.
Are the staff aware of triggers for behaviour?	• Identify, observe and document triggers and use consistent approach to prevent behaviour. • Does challenging behaviour happen after relatives have visited? • Refer to specialist mental health services for functional analysis and behavioural interventions.
Getting used to a new place May take up to 6 weeks for people to feel settled	• Get information from family and/or previous care facility of what has helped in the past. • Personal belongings in room. • Consistency of 2-3 key workers for most of personal care for first few weeks (check if prefers male/female).
Confusion linked to physical design of the home	• Enable good lighting, use of pictures and colours to find way around, clear signage to toilets, good access to personal objects, outside space, etc.
Reactions to uncomfortable temperatures	• If very hot consider increasing fluids, use of fans and garden. • If cold use of blankets, extra clothing.

POSSIBLE CAUSE: Lack of understanding of how the person sees and interprets their world	
Challenging behaviour may result from:	**Ideas for staff:**
Person unable to communicate their needs or requests are being ignored.	• Be proactive with checking person's needs at frequent intervals. • Use short simple sentences or statements or non-verbal gestures to indicate walking to toilet, etc.
Hearing and visual difficulties	• Check for sensory impairment. • Check which is their 'best' ear, or if they have visual impairment on one side then approach from the other. • Optician/audiology (home visits possible).
Difficulties in recognizing everyday objects	• Use alternative means to aid recognition, e.g. flushing toilet, holding the object, carer to demonstrate use of object.
Repetitive behaviours	• Use distraction, reassurance, emotion-focused strategies.
Disinhibition **Typically frontal lobe related**	• Use distraction techniques and alternative means of meeting needs. • Observe for time of day and notice triggers.
Experiencing delusions and visual hallucinations symptoms of Frontal dementia, Lewy Body, vascular dementia and dementia linked with Parkinson's	• Take personal care tasks slowly and give repeated reassurance about intentions. • Acknowledge the delusion / hallucination – don't ignore or try to prove to the person they are wrong. • If they are not concerned or anxious about it then don't dwell on it. • Ensure plenty of reassurance if person is worried and ensure there are alternative activities to be involved in. • Consider referral to specialist services for further assessment/ treatment.

POSSIBLE CAUSE: Lack of awareness of person's belief and lifestyle preferences

Challenging behaviour may result from:	Ideas for staff:
Lack of knowledge about the person and their beliefs and preferences.	• Consider using life story templates e.g. 'This is Me' and 'My Life Story' to gather information. • Promote respect for religious or cultural rules and customs. • Consider whether person thinks they are younger with work or care responsibilities, e.g. need to collect children from school or go to work. • Offer alternative meaningful activity which will be valued by person. Acknowledge where the person is at – don't argue or attempt to change their viewpoint. • Check attitudes towards physical touch. • Consider beliefs about people of different age, gender, race/colour. • Promote work with family members to inform care and better understand the resident.

POSSIBLE CAUSE: Underlying emotional or mental health problems

Challenging behaviour may result from:	Ideas for staff:
Undiagnosed depression and anxiety GP to use Cornell Depression Scale to assess Depression is a common symptom of all dementias and is often undiagnosed and not treated	• Ensure resident has access to activities and ACTIVELY encourage participation. • Promote active involvement of relatives in care. • Be aware of triggers for anxiety, e.g. confined places.
The person may be searching for their loved ones.	• Try to provide the person with a sense of control and safety and ask them about their loved ones. • Try using life story information and photos to reinforce sense of identity and enhance memories.
Experience of bereavement or effects of traumatic events in their life	• Enable safe expression of emotions using validation, rather than lying or confronting person with the reality of their loved one's absence. • Check with family what works. • Enable usual coping behaviours, e.g. safe walking. • Consider using dolls and pets.
Disorientation and memory problems	• Try to make the most of the person's strengths and remaining abilities.

1.2 The role of pain management in the treatment of BPSD

Pain in older people is under-recognised and under-treated.[6] Untreated persistent pain can have a major impact on physical function and psychosocial function which can result in depression, anxiety, agitation, social withdrawal, increased risk of falls, loss of appetite, sleeplessness. This is of particular significance in dementia patients where the untreated pain can be a trigger for other manifestations of BPSD.

In a care setting the following key principles should be applied:

1. The assessment of pain should be routine for all residents/patients.
2. Validated pain assessment tools should be used, which are appropriate for that individual i.e. taking into consideration their ability to communicate pain and their level of cognitive function.
3. Care staff should be trained on the use of pain assessment tools and be able to use them confidently.
4. The pain assessment should be conducted before and after analgesia is administered to ensure the effectiveness of the prescribed medication.
5. There should be a systematic approach to assessing the patient, what has been observed and what has been required to alleviate pain or distress, should be clearly documented, e.g. re-positioning, re-assurance and analgesia.
6. Just because a person has cognitive impairment does NOT mean they automatically cannot use self-report scales for pain. Generally residents with MMSE (Mini Mental State Examination) score of 18 or more can use self-report pain scales.
7. If the person cannot communicate their needs then the views of the person who knows them best about whether they are in pain or not must be included in the assessment.

Described on the following pages are examples of three tools for assessing pain in people with dementia who are unable to verbalise their needs. The Abbey pain scale and Doloplus 2 scale are used mainly in care settings.

These tools (Attachments 2-4) are available to download seperately from the PrescQIPP website:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

1.3 Pain assessment in advanced dementia (PAINAD) scale[7]

An adaptable Word version of this tool (Attachment 2) is available on the PrescQIPP website: http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

ITEMS*	0	1	2	SCORE
Breathing independent of vocalisation	Normal	Occasional laboured breathing. Short period of hyperventilation.	Noisy laboured breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalisation	None	Occasional moan or groan. Low level speech with a negative or disapproving quality.	Repeated troubled call out. Loud moaning or groaning. Crying	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			TOTAL**	

*Five-item observational tool (see the description of each item below).

**Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0=”no pain” to 10=”severe pain”).

Instructions

Observe the patient for 5 minutes before scoring his or her behaviour. (Subjects in the pilot study were observed for 5 minutes, but a clear recommendation for length of observation has not been provided by the developers of this tool.)

The patient can be observed under different conditions, e.g. at rest, during a pleasant activity, during care giving, after the administration of analgesia.

The developers have not given any specific guidance on the treatment of pain according to each score however any item scored as 1 or 2 indicates that the person is in some type of discomfort and therefore steps should be taken to alleviate this.

Breathing

Normal breathing is characterised by effortless, quiet, rhythmic (smooth) respirations.

Occasional laboured breathing is characterised by episodic bursts of harsh, difficult or wearing respirations.

Short period of hyperventilation is characterised by intervals of rapid, deep breaths lasting a short period of time.

Noisy laboured breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.

Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.

Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnoea (cessation of breathing).

Negative vocalisation

None is characterised by speech or vocalisation that has a neutral or pleasant quality.

Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterised by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.

Pain assessment in advanced dementia (PAINAD) scale

Low level speech with a negative or disapproving quality is characterised by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.

Repeated troubled calling out is characterised by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.

Loud moaning or groaning is characterised by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterised by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.

Crying is characterised by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial expression

Smiling is characterised by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment.

Inexpressive refers to a neutral, at ease, relaxed, or blank look.

Sad is characterised by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.

Frightened is characterised by a look of fear, alarm or heightened anxiety. Eyes appear wide open.

Frown is characterised by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.

Facial grimacing is characterised by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body language

Relaxed is characterised by a calm, restful, mellow appearance. The person seems to be taking it easy.

Tense is characterised by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).

Distressed pacing is characterised by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.

Fidgeting is characterised by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.

Rigid is characterised by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).

Fists clenched is characterised by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.

Knees pulled up is characterised by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).

Pulling or pushing away is characterised by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.

Striking out is characterised by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

No need to console is characterised by a sense of well being. The person appears content.

Distracted or reassured by voice or touch is characterised by a disruption in the behaviour when the person is spoken to or touched. The behaviour stops during the period of interaction with no indication that the person is at all distressed.

Unable to console, distract or reassure is characterised by the inability to soothe the person or stop a behaviour with words or actions. No amount of comforting, verbal or physical, will alleviate the behaviour.

Acknowledgement

The PAINAD was developed and tested by clinicians and researchers at the New England Geriatric Research Education and Clinical Center, a Department of Veterans Affairs center of excellence with divisions at EN Rogers Memorial Veterans Hospital, Bedford, MA, and VA Boston Health System.

It is important that those using the pain assessment tool have been trained on its use and are able to use it confidently. Training should be sourced locally by providers/commissioners as appropriate.

1.4 Abbey Pain Scale

Use of the Abbey Pain Scale

The Abbey Pain Scale is best used as part of an overall pain management plan.

Objective

The Pain Scale is an instrument designed to assist in the assessment of pain in residents who are unable to clearly articulate their needs.

Ongoing assessment

The Scale does not differentiate between distress and pain, so measuring the effectiveness of pain-relieving interventions is essential. It has been recommended that the Abbey Pain Scale be used as a movement-based assessment. The staff recording the scale should therefore observe the resident while they are being moved, e.g. during pressure area care, while showering etc.

Complete the scale immediately following the procedure and record the results in the resident's notes. Include the time of completion of the scale, the score, and staff member's signature and action (if any) taken in response to results of the assessment, e.g. pain medication or other therapies.

A second evaluation should be conducted one hour after any intervention taken in response to the first assessment, to determine the effectiveness of any pain-relieving intervention. If, at this assessment, the score on the pain scale is the same, or worse, consider further intervention and act as appropriate, complete the pain scale hourly, until the resident appears comfortable, then four-hourly for 24 hours, treating pain if it recurs. Record all the pain-relieving interventions undertaken. If pain/distress persists, undertake a comprehensive assessment of all facets of resident's care and monitor closely over a 24-hour period, including any further interventions undertaken. If there is no improvement during that time, notify the medical practitioner of the pain scores and the action/s taken.

Jenny Abbey

April, 2007

An adaptable Word version of this tool (Attachment 3) is available on the PrescQIPP website:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

The Abbey Pain Scale: For measurement of pain in people with dementia who cannot verbalise

How to use the scale: While observing the resident, score questions 1 to 6, using the scale provided.

Name of resident:				
Name and designation of person completing the scale:				
Date:		**Time:**		
Latest pain relief given was:		**at**		**hours**

SCALE: Absent = 0 Mild = 1 Moderate = 2 Severe = 3

	Question	**Score**
1	**Vocalisation,** e.g. whimpering, groaning, crying	
2	**Facial expression**, e.g. looking tense, frowning, grimacing, looking frightened	
3	**Change in body language,** e.g. fidgeting, rocking, guarding part of body, withdrawn	
4	**Behavioural change,** e.g. increased confusion, refusing to eat, alteration in usual patterns	
5	**Physiological change,** e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor	
6	**Physical changes,** e.g. skin tears, pressure areas, arthritis, contractures	
Add score of questions 1-6 and record here	**TOTAL PAIN SCORE**	

Now tick the box that matches the TOTAL PAIN SCORE

0-2 = No pain	**3-7 = Mild**	**8-13 = Moderate**	**14+ = Severe**

Finally tick the box that matches the type of pain

Chronic	**Acute**	**Acute on chronic**

Acknowledgement

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B. Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002

This document may be reproduced with this acknowledgment retained.

It is important that those using the pain assessment tool have been trained on its use and are able to use it confidently. Training should be sourced locally by providers/commissioners as appropriate.

1.5 DOLOPLUS 2 Scale

An adaptable Word version of this tool (Attachment 4) is available on the PrescQIPP website:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

This tool is used for those with dementia who cannot verbalise their needs.

It is based on a change in behaviour to what is normal. If the person cannot communicate their needs then the views of the person who knows them best about whether they are in pain or not must be included in the assessment.

SOMATIC REACTIONS		
Pain expressed through words, or gesture, tears/ moaning	No complaints of pain by any means	**0**
	Complaints of pain only when asked	**1**
	Complaints of pain occasionally even when not asked	**2**
	Complaints of pain continuously noticed even when not asked	**3**
Unusual protective body position adopted at rest	No protective body posture observed	**0**
	The person occasionally avoids certain positions due to pain	**1**
	The person often tries to find a protective position and when they do, has pain relief	**2**
	The person continuously tries to find a protective position without achieving pain relief	**3**
Protection of sore area by defensive action or gesture	No protective action taken	**0**
	Attempts by resident to protect sore area but this doesn't interfere with care delivery	**1**
	Attempts by resident to protect the area which does interfere with care delivery	**2**
	Protective action/s taken by resident at rest, even when not approached	**3**
Facial expression: Grimace, drawn or atonic	Usual expression	**0**
	Expression showing pain when approached	**1**
	Expression showing pain even without being approached	**2**
	Permanent and unusually blank look (voiceless, staring, looking blank)	**3**
Sleep pattern	Normal sleep	**0**
	Difficult to go to sleep	**1**
	Frequent waking (restlessness)	**2**
	Insomnia affecting how awake they are in the day	**3**

PSYCHOMOTOR REACTIONS		
Washing and/ or dressing	Usual abilities and activities remain unaffected	**0**
	Usual abilities slightly affected (may need more help) as a result of discomfort	**1**
	Usual abilities and washing, and/or dressing is much more difficult	**2**
	Level of pain makes washing and/or dressing very difficult/impossible to complete	**3**

DOLOPLUS 2 Scale

PSYCHOMOTOR REACTIONS		
Mobility	Usual abilities and activities remain unaffected	**0**
	Usual activities reduced (person avoids certain movements and reduces walking distance)	**1**
	Usual activities and abilities reduced (even with help the patient cuts down on movements)	**2**
	Any movement is impossible, the patient resists all persuasion	**3**

PSYCHOSOCIAL REACTIONS		
Communication	Unchanged	**0**
	Heightened (the person demands attention in an unusual manner)	**1**
	Lessened (the person cuts him/herself off)	**2**
	Absence or refusal of any form of communication	**3**
Social life, includes appetite	Participates at their normal level of activity (meals, entertainment, therapy)	**0**
	Needs more encouragement than usual to participate in activities or eat food	**1**
	Sometimes refuses to participate in the activity and/or refuses usual amount of food	**2**
	Refuses to participate in anything and does not eat (a change from usual)	**3**
Problems of behaviour	Normal behaviour for this person	**0**
	Development of occasional behaviour which has negative consequences	**1**
	Development of frequent behaviour which has negative consequences	**2**
	Development of continuous behaviour which has negative consequences	**3**
	SCORE - A score of five or more indicates pain	

Acknowledgement

Adapted from: Lefebvre-Chapiro and the DOLOPLUS2 group (2001)

It is important that those using the pain assessment tool have been trained on its use and are able to use it confidently. Training should be sourced locally by providers/commissioners as appropriate.

1.6 & 1.7 Helping someone with dementia who is distressed or behaving unusually

The following leaflet is available in two versions as stand alone PDFs (Attachments 5 and 6) on the PrescQIPP website:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

We have only included the leaflet for relatives and/or carers in this toolkit as there are only minor differences between the two leaflets. The version for care home staff is Attachment 6, which can be accessed via the link above. In the care home staff version the meaning of 'U' is 'understanding' rather than 'you', which is the meaning in the leaflet below.

Leaflet for relatives and/or carers of people with dementia

There are often good reasons why someone with dementia is distressed or behaving unusually. However, they might not always be able to tell you what's troubling them.

The challenge is to work out what the cause is and what you can do to help, for the benefit of both of you. Sometimes we react to unusual behaviour without knowing what the person might need or be saying through their behaviour.

We have used the ideas of **"STOP"** and **"PAUSE"** to describe the key ways to help you listen and watch, in order to understand distress and unusual behaviour.

You may need to try some things for several weeks before you see improvement. If distress or behaviours do not resolve with the advice given on the following pages, consult your doctor or ask for a referral to your local specialist mental health services.

Further advice

The Alzheimer's Society has more advice and information for people with different types of dementia, not just Alzheimer's dementia.

You can go to the Alzheimer's Society website at: www.alzheimers.org.uk or call them on their helpline (freephone) on 0300 222 11 22.

We have listed useful factsheets on particular behaviours at the end of this leaflet.

If you would like further help, please don't struggle on your own as there are many ways in which people in your situation can be helped. Please contact your local Alzheimer's Society or your doctor for advice. If you want information on how services can help you, see 'How health and social care professionals can help': http://alzheimers.org.uk/factsheet/454

Before you respond

&

S	See things from the point of view of person with dementia.
T	Think about your own thoughts and feelings.
O	Observe and ask what the person is trying to communicate and what is going on.
P	Patience and persistence.

P	Physical
A	Activity
U	You (Understanding in care homes version)
S	Self-esteem
E	Emotion

P is for PHYSICAL

Are they in pain?

Pain can be a common cause of changes in behaviour and can result from many problems such as joint pain, dental problems or discomfort from skin problems or constipation.

What to do

- Ask the person if they are in pain.
- Watch out for signs of them being in pain.
- Change their position if they have been sitting in one place for a long time.
- If you think they are in pain get advice from their doctor. Note the activity they're doing when they are distressed or seem uncomfortable so you can give information to their doctor.
- Please seek advice from their doctor if the person is taking any medication for pain, either prescribed or purchased. It may be that prescribed pain-killers need adjusting or that those being self-medicated are unsuitable.

See factsheet 'Pain in dementia' on the Alzheimer Scotland: Action on Dementia website or http://www.alzscot.org/downloads/IS38pain%20in%20dementia.pdf

Has their medication been reviewed or changed recently? Are they taking all their medication correctly?

New medicines might be causing side-effects. Older medicines may no longer be needed or may need adjusting. Incorrect use of medication may result in extra side-effects or result in limited or no expected benefits.

Do they have an infection?

They might have an infection such as urinary tract or chest infection or cellulitis.

What to do?

Look out for things like smelly or cloudy urine (wee) or an unusually wheezy chest or redness, itchiness or soreness of the vagina (women) or penis (men) and report these to their GP.

Are they hungry or thirsty?

Dementia can cause changes in taste and appetite. People may have difficulty managing or recognising food or cutlery. Dehydration (lack of liquid) can happen with changes between hot and cold weather. People may avoid drinking in order to avoid going to the toilet.

What to do

- Note any problems with eating or drinking.
- People may need prompting to use cutlery, such as putting a fork in their hand and guiding their hand to the food.
- Meals may need to be little and often to ensure that blood sugar is maintained.
- Look for very yellow urine, which is a sign that they ought to be drinking more. Encourage drinking and provide support for going to the toilet if needed (see advice in Self-esteem below).
- Look for problems with denture pain or mouth ulcers.
- Let their GP know if you are concerned about how much they are eating or drinking.

See factsheet ‘Eating and drinking’: http://alzheimers.org.uk/factsheet/511

Are they getting enough sleep at night?

Dementia can cause changes in people’s sleep schedule so that they wake up more often and stay awake for longer at night. Confusion about time can lead them to think it is daytime at 4am and want to get dressed.

What to do

- Note any signs of pain or discomfort upon waking.
- Keep bedtime routines and provide nightlights and comfort objects.
- Avoid watching TV in the bedroom or the person spending long periods in time in bed while awake; use bed only for sleep.
- Encourage outdoor exercise or activities to keep them alert during the day.
- Try to stop or reduce daytime napping.
- Avoid alcohol and caffeine before bedtime.
- See their GP if problems persist.

Could they have hearing or eyesight problems?

People can become disinterested in a conversation or an activity just because they cannot see or hear easily.

What to do

- Check how well they can see or hear things, even if they have glasses or a hearing aid.
- Improve the lighting.
- Make sure that you talk loudly and clearly into the good ear.
- Avoid competing noises or activities such as TV or radio.
- Try to move slowly and approach the person from the side where the eyesight and/or hearing are best.
- Get advice from an optician or hearing specialist if you think their sight or hearing could be improved.

Could they be making ‘visual mistakes’?

People with dementia might still have good vision but have problems with making sense of things correctly in front of them (called visuospatial difficulties). This might make it difficult for them to watch TV, use objects correctly or walk confidently. Other examples include misinterpreting reflections in mirrors or avoid stepping on shiny floor because it looks wet or slippery.

What to do

- Improve the lighting.
- Make sure the rooms are free from clutter and there is space to move around with confidence.
- Cover-up or change busy patterns on walls and floors.

Could they be experiencing hallucinations?

Hallucinations may occur with some types of dementia, especially dementia with Lewy bodies. Visual hallucinations are most common and involve seeing things that are not present, usually people and animals. This can be frightening and lead to changes in behaviour.

What to do

- If they are not worried then don’t dwell on it.
- Listen carefully and acknowledge what the person is saying.
- Talk calmly and try not to argue with them.
- Consult their GP if the hallucinations persist or worsen or are frightening.

Could the room temperature be too hot or too cold?

What to do

If very hot and the temperature cannot be reduced consider giving them more drinks, use fans or sit them outside in the shade. If cold, try the use of blankets and extra clothing.

A is for ACTIVITIES

Could they be bored or needing social contact?

What to do

- Use simple activities to prompt conversation, such as looking at a vase of flowers, a picture on the wall or looking out of the window.
- Involve them in everyday activities like laying the table.
- Try and do activities they used to enjoy doing, e.g. gardening or visiting the seaside.
- Give the person regular opportunities to talk to someone.

- Visit your local dementia café where both of you can meet and chat with others in a similar situation (contact your local Alzheimer's Society for more information).
- Develop a "life story" together to support reminiscing and conversations. Find life story forms at: http://www.dementiauk.org/assets/files/info_and_support/Dementia_UK_Life_Story_Template_final.doc

Is there too much going on or is the person in unfamiliar surroundings with people they don't recognise?

What to do

- Consider having more routine and structure in the day by doing the same things at the same time everyday.
- Have a quiet time or use calming activity or music, especially at times they are tired, such as after lunch.

U is for YOU (or UNDERSTANDING in the care home staff version)

Are you looking after yourself?

Your situation may be extremely difficult to cope with and you may feel helpless and frustrated. It is important that you look after your physical health and have support. It's important that you do not take all the responsibility for managing very demanding situations.

See factsheet 'Carers: Looking after yourself' at: http://alzheimers.org.uk/factsheet/523

What to do

Try to share the responsibilities with others and accept help from family, friends, neighbours or professionals.

Do you understand why they are distressed or behaving badly?

You may struggle to understand someone's changing behaviour. How you understand the behaviour is crucial to how you will react. If you blame the person, you are more likely to get angry.

What to do

- Try and find out as much as you can about dementia and what causes certain behaviours.
- Try to avoid taking things personally or having arguments over mistaken ideas or attempt to change their viewpoint. Your arguments will only end up frustrating you and probably upsetting them.
- Be mindful of your own tone and facial expressions and try to speak calmly.

S is for SELF ESTEEM

Are they frustrated because they are unable to communicate their needs or they can no longer do the things they used to do?

People with dementia can find it difficult to feel good about themselves. This can often be expressed through unusual behaviours.

What to do

- Include people in conversations and be aware of how they might be feeling.
- Let the person finish their sentences unless they ask for your help.
- Don't point out their mistakes.

- Let them do jobs they are used to doing, e.g. putting some of the shopping away. Break the job down into smaller steps to help them. This will help them feel they are doing something useful.
- Explain what you plan to do or what you are doing.
- Ask them questions which require yes/no responses and give plenty of time to respond.
- Help the person recognise objects. Do this by showing them how to use the object, getting them to touch the object or using noise, e.g. flushing toilet.
- Use short simple statements rather than questions or gestures to indicate walking to the toilet, etc. For example, say “come to the toilet” rather than “would you like to go to the toilet”?

See factsheet ‘Communicating’ at http://alzheimers.org.uk/factsheet/500

E is for EMOTIONS

Are they sad, scared, depressed or anxious?

People with dementia still experience feelings and emotions even though they may not be able to explain to you their feelings or remember what caused them to feel that way.

What to do

- Note down what was going on to see if something triggers the change in feelings or mood. This might be due to certain music, noises or a visit from someone.
- Encourage distracting activities such as walking.
- Touching or holding their hand may help calm them and show them you care.
- Try to pick out key words or phrases and repeat these back as it may help the person focus on a particular topic.
- Respond to the person’s feelings rather than correcting the accuracy of what they are saying. For example, if someone says they miss their mother, think about the meaning behind what they are saying. Are they sad or worried about something? You could encourage them to tell stories about their mother and what they miss about her to help them feel more secure. You might need to make try out different ways of responding to see what works best.

If someone’s low or anxious feelings or mood persists, ask their doctor for a referral to specialist mental health services.

Other useful factsheets

Unusual behaviour	http://alzheimers.org.uk/factsheet/525
Coping with incontinence	http://alzheimers.org.uk/factsheet/502
Dressing	http://alzheimers.org.uk/factsheet/510
Sex and dementia	http://alzheimers.org.uk/factsheet/514
Moving and walking about	http://alzheimers.org.uk/factsheet/501
Washing and bathing	http://alzheimers.org.uk/factsheet/504
Dealing with aggressive behaviour	http://alzheimers.org.uk/factsheet/509
Visuoperceptual difficulties	http://www.alzheimers.org.uk/factsheet/527
Hallucinations	http://www.alzheimers.org.uk/factsheet/520

1.8 The ‘Good Sleep Guide’ for people living with dementia: Information for carers

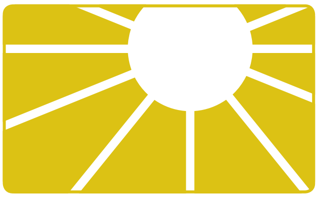
This document is available as a stand alone PDF (Attachment 7) that can be downloaded from the PrescQIPP website:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Causes of sleep disturbances

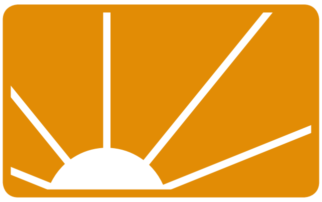
- Changes in the brain can cause restlessness and sleep disturbance.
- Physical health problems such as urine infections or prostate problems.
- Pain or discomfort, such as arthritis.
- Reduced need for sleep as part of normal ageing or sleeping too much during the day.
- Nightmares and waking up with anxiety and confusion.
- Environmental factors such as noise or feeling too hot or cold.

During the day



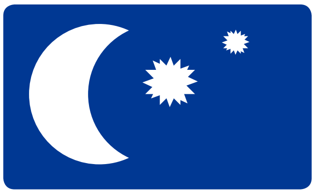
- Try to encourage the person with dementia to get adequate exercise during the day. Generally trying to keep fit helps.
- Natural light aids the body’s natural day-night rhythm. Try and ensure that he or she gets adequate natural light by spending some time outside or sat near a window. This is particularly important in the winter.
- Providing adequate lighting (artificial or natural) throughout waking hours is also important.

During the evening



- If possible encourage the person living with dementia to take some light exercise or activity early in the evening. Encourage him or her to wind down during the course of the evening. Try not to let them do anything that is mentally demanding within 90 minutes of bedtime.
- Try to keep the topic of conversation lively and positive without dwelling on any problems that have occurred during the day. Reassure the person living with dementia that all is well and it is now time to relax.
- Discourage sleeping or dozing in the armchair if possible. Try and keep sleep for bedtime.
- Do not give the person living with dementia too much tea, coffee or other drinks containing caffeine. Only give them a light snack for supper. Do not give them alcohol to drink to aid their sleep – it usually does the opposite. If they are a smoker, try to discourage him or her from smoking during the evening and doing so just before bed.
- Consider whether medication might be causing sleep problems – dementia medication can cause night-time stimulation or disturbed sleep. Consider taking the medication in the morning or earlier in the day. If you are unsure, ask advice from his or her pharmacist or doctor.

At bedtime



- Try to establish a regular routine - use regular bedtime ‘cues’ such as the 10 o’clock news, turning off some lights to signal bedtime or by using familiar routines.
- If you need to, explain in a clear and calm manner that it is bedtime, for example, “It’s 10 o’clock now – it’s time to put your pyjamas on”. If you need to, follow-up on what you are saying by showing the person what to do at each stage, e.g., show them their pyjamas to put on, and so on.

- Try to encourage the person to go to bed at a regular time or when they show signs of tiredness but discourage them from starting to go to bed earlier and earlier in the evening.
- Make sure the bed and bedroom are comfortable – not too cold and not too warm.
- Discourage reading or watching TV in bed. Keep these activities for another room.
- Put the main lights out when the person living with dementia gets into bed. Use a dim nightlight to help the person find their way to the bathroom or find their way around.
- Try playing soft music as the person goes to sleep.
- Set the morning alarm for the same time every day, seven days a week, at least until their sleep pattern settles down.

If they have problems getting to sleep

- If the person continues to refuse to go to sleep at a reasonable time then try to be flexible – make sure the house is safe if they walk around at night or let them sleep on the sofa. Let them carry-out any rituals that they need to in order to calm down.
- It may help the person to recognise that it is bedtime if you wear night-clothes yourself, even if you are not ready for bed, as this acts as another ‘cue’ for bedtime.
- Remember that sleep problems are quite common and they are not as damaging as you might think. Try not to let yourself or the person living with dementia get upset or frustrated.
- You may decide to sleep in separate beds or rooms so that you can get a well-deserved good night’s sleep.
- Have realistic expectations about the person’s sleeping pattern; people with dementia often have disturbed sleep but may get enough sleep over a 24 hour period.
- A good sleep pattern may take a number of weeks to establish. Be confident that the person living with dementia will be helped to achieve this by working through The Good Sleep Guide.

SECTION 2

Guidance and supporting tools for GPs on reviewing and stopping antipsychotics in people living with dementia

Sections 2.1-2.3 are available as an adaptable Word document (Attachment 8) and can be found on the PrescQIPP website:
http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

2.1

Guidance for GPs on reviewing and stopping antipsychotics prescribed for behavioural and psychological symptoms of dementia (BPSD)

1. All patients with dementia currently on antipsychotics for behavioural problems who have not had a trial discontinuation in the last 3 months should have the antipsychotic reviewed and stopped to assess the risks and benefits of continued treatment unless:
    - The antipsychotic was prescribed for a pre-existing condition prior to a diagnosis of dementia, e.g. bipolar disorder or psychotic depression.
    - The patient is under regular review by a specialist for behavioural problems. This does not include reviews solely planned to assess the on-going benefits of prescribing cholinesterase inhibitors (e.g. donepezil) to delay cognitive decline.
    - There is a detailed care plan in place for ongoing antipsychotic use.

2. There may be some patients with undiagnosed dementia prescribed antipsychotics that need reviewing. Consider running a report on patients on an antipsychotic to discover those that do not have a linked diagnosis requiring antipsychotics.

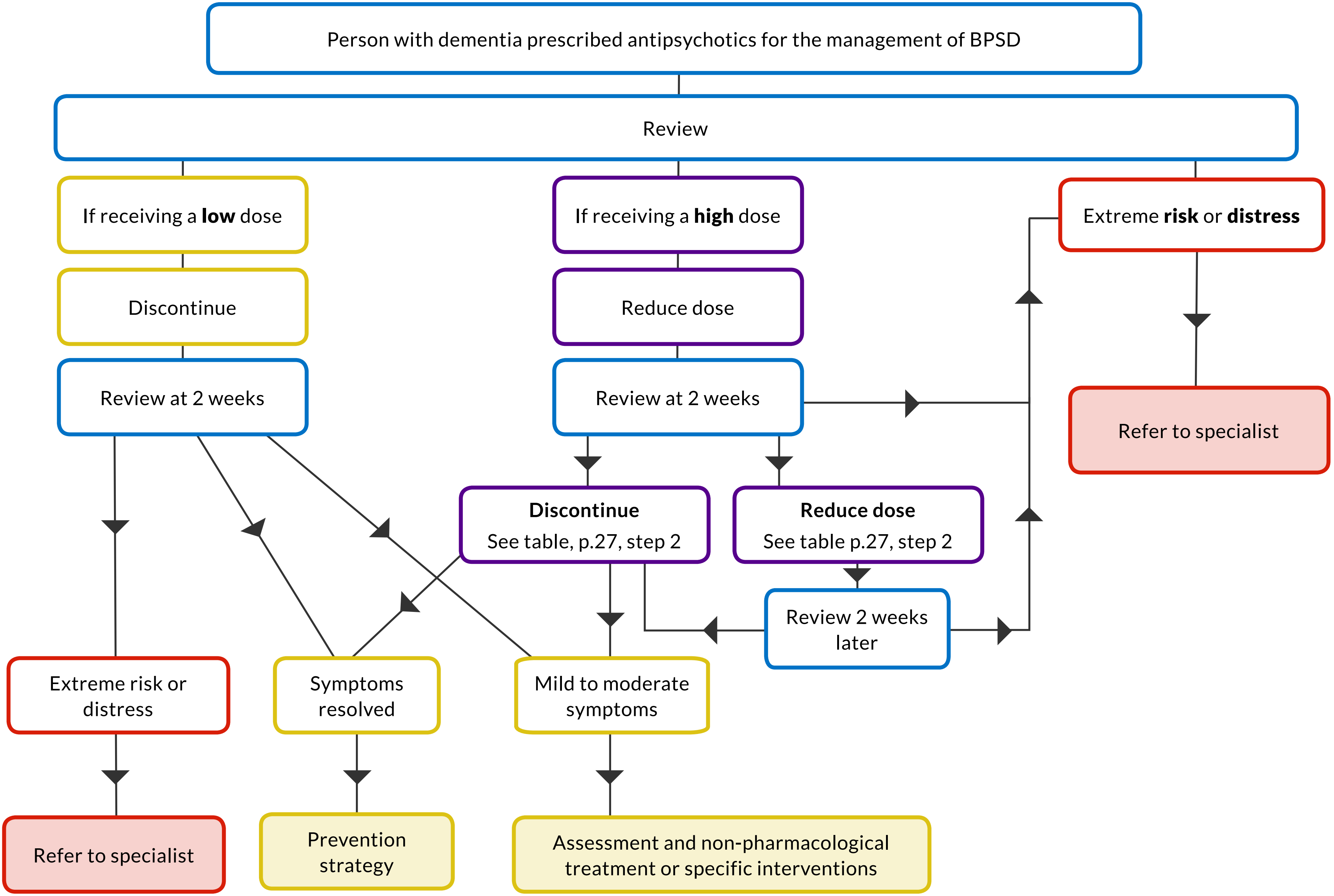
3. If the patient is under regular review by secondary care for behavioural problems then responsibility for reviewing and reducing or stopping the antipsychotic lies with secondary care, otherwise this should be undertaken by the patient's GP.

4. If a decision is made to reduce or stop an antipsychotic, carers should be involved in the decision and supported through the process.

5. Carers should be:
    - Given information on why the treatment is being stopped, including a written leaflet or information in another suitable format.
    - Asked to keep a diary of the patient's behaviour from a week before stopping or reducing the dose to a week after the reduction or stop date to assess the impact more objectively of reducing and/or stopping the treatment
    - Given a contact number in case the patient's behaviour deteriorates significantly.
    - Left with a small supply of the drug, which can be reinstated if agreed with the prescriber

2.2 Suggested pathway for a person who has already been prescribed antipsychotic drugs[3] (adapted)

Monitoring



Person with dementia prescribed antipsychotics for the management of BPSD

Review

If receiving a **low** dose

Discontinue

Review at 2 weeks

If receiving a **high** dose

Reduce dose

Review at 2 weeks

Extreme **risk** or **distress**

Refer to specialist

Discontinue
See table, p.27, step 2

Reduce dose
See table p.27, step 2

Review 2 weeks later

Extreme risk or distress

Symptoms resolved

Mild to moderate symptoms

Refer to specialist

Prevention strategy

Assessment and non-pharmacological treatment or specific interventions

2.3 Suggested protocol for reducing and stopping antipsychotics

An adaptable version of this document (Attachment 8) can be found on the PrescQIPP website: http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

If the person is receiving a "low dose" proceed directly with discontinuation and monitoring.

Antipsychotic	Suggested daily low dose*
Aripiprazole	Less than 5mg
Olanzapine	Less than 2.5mg
Quetiapine	Less than 50mg
Risperidone	Less than 0.5mg
Haloperidol	Less than 0.5mg
Amisulpiride	Less than 50mg

*Suggested "low dose", but consult the BNF www.bnf.org

1. If the person is receiving a higher dose, taper the dose over one month:
   - Reduce to half dose for two weeks
   - GP review at two weeks
   - Discontinue immediately after a further two weeks
   - Review every stage of dose reduction to evaluate patient response
   - If a very high dose was recommended by secondary care, get advice from them before making any changes. The following is a guide for the most commonly used medicines, but individual patient circumstances and the views of the carer may need to be taken into consideration.

Drug	Total daily dose	Step 1	Step 2	Step 3
Risperidone	Up to 500 micrograms	**Stop**		
	Up to 1mg	Halve dose	**Stop**	
	Over 1mg	Halve dose	Halve dose	**Stop**
Quetiapine	25mg	**Stop**		
	Up to 50mg	Halve dose	**Stop**	
	Over 50mg	Halve dose	Halve dose	**Stop**
Haloperidol	Up to 500 micrograms	**Stop**		
	Up to 1mg	Halve dose	**Stop**	
	Over 1mg	Halve dose	Halve dose	**Stop**

2. In some cases it may[5] be necessary to withdraw the drug more slowly, particularly if symptoms reappear.
   - Implement small decreases in dose (ensure dose reduction is possible with strengths available), one step down at a time.
   - Where the antipsychotic is given more than once daily, decrease only one dose to start with, choosing the dose where patient likely to be least affected.
   - Allow sufficient time for the patient to adapt to the new dose (usually 1-2 weeks) before considering the next small reduction in dose.
   - When the lowest dose has been achieved on a daily basis then administer on alternate days before stopping completely.

3. A minimum of two weeks should be left between any dose reduction and a review to consider stopping or a further dose reduction, though longer periods can be allowed if there are clinical or carer concerns.
4. If behavioural problems continue then other strategies should be considered instead of, or alongside, a short six-week course of antipsychotics such as regular pain relief or behavioural strategies, based on an individual assessment.
5. If antipsychotics are reinstated this should only be done if the benefits outweigh the risks for that individual patient. Consider starting low again, even if the dose stopped was higher.
6. If a decision is made to continue the antipsychotic beyond this first six weeks then all future treatment should be prescribed as courses, up to a maximum of three months, with a suggested stop date of a Monday, so benefits and risks can be reassessed at regular intervals in the working week.
7. Risperidone is currently the only licensed antipsychotic in dementia, for short-term treatment (up to 6 weeks) of persistent aggression in patients with moderate to severe Alzheimer's disease unresponsive to non-pharmacological interventions and when there is risk of harm to self or others. Alternative antipsychotic drugs include olanzapine, aripiprazole and quetiapine. The evidence relating to these drugs is more limited. Of particular note, evidence shows that quetiapine is ineffective in treating behavioural and psychological symptoms in dementia and cholinergic side-effects may be a particular concern.[3]
8. If an antipsychotic is indicated, weekly monitoring of sedation, fluid intake and early indicators of chest infection is strongly recommended.[3]

TOP TIPS

It is recommended that when reviewing a number of patients in a care home, the stopping of treatment is staggered and those patients considered to be the most likely **to not need the antipsychotic are stopped first**, to give the home confidence in the process.

Bear in mind that in the elderly it is good practice to only change one medicine at a time when deciding whether to reduce or stop an antipsychotic.

Any stop date should usually be planned for a Monday so that if behavioural symptoms reappear these can be assessed during the working week.

If the antipsychotic is stopped, make sure the repeat prescribing record is updated to prevent a further supply being prescribed.

For support or advice on reducing, stopping or restarting antipsychotics the following people/teams can be contacted.

Name of individual or team	Contact details	Other relevant information i.e. working hours

2.4 Audit of patients diagnosed with dementia on antipsychotics

An adaptable Excel version of this audit (Attachment 9) can be found on the PrescQIPP website:
http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Instructions

Gather the audit information using the questions below, then identify what further action(s) need to be taken.

Patient identifier	Gender	Living where (note 1)	Dementia type (note 2)	Anti-psychotic Yes/No (note 3)	If yes, name? (note 4)	Other diagnosis (notes 5 & 6)	Date antipsychotic first prescribed by a GP YY/MM) (note 7)	Date anti-psychotic last reviewed (note 8)	Date for stopping anti-psychotic (note 9)	Date for review (note 9)	Is there a detailed care plan covering the antipsychotics use? Yes/No	Is the patient being reviewed regularly by secondary care? Yes/No

Notes

1. ‘Living where’ codes: At home (H), in a nursing home (N), residential home (R)
2. Type of dementia codes: Alzheimer’s (A), Lewy body (L), Vascular (V), Parkinson’s (P), Mixed (M) or not recorded (NR)
3. **If no, the audit is complete for this patient.**
4. Antipsychotic codes: Risperidone (R), olanzapine (O), quetiapine (Q), aripiprazole(A), haloperidol (H), if another drug please name in full
5. If the antipsychotic is prescribed for a diagnosis other than BPSD, e.g. bipolar disease, please record this diagnosis.
6. **If the antipsychotic is for another diagnosis the audit for this patient is complete.**
7. Record as either year then month (YY/MM) or not recorded (NR)
8. Record as either year then month (YY/MM) or started recently (SR) or not recorded (NR)
9. Record the date or NA for ‘not applicable’

2.5 Audit of patients on antipsychotics with no diagnosis relating to a licensed indication other than dementia for risperidone

An adaptable Excel version of this audit (Attachment 10) can be found on the PrescQIPP website:
http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Instructions

Gather the audit information using the questions below, then identify what further action(s) need to be taken.

Patient identifier	Gender	Living where (note 1)	If a diagnosis of dementia, what type? (note 2)	Anti-psychotic (note 3)	Date anti-psychotic first prescribed by a GP (YY/MM) (note 4)	Date anti-psychotic last reviewed (note 5)	Date for stopping anti-psychotic (note 6)	Date for review (note 6)	Is there a detailed care plan covering the anti-psychotics use? Yes/No	Is the patient being reviewed regularly by secondary care for behavioural problems? Yes/No (note 7)

Notes

1. ‘Living where’ codes: At home (H), in a nursing home (N), residential home (R).
2. Type of dementia codes: Not diagnosed (ND), Alzheimer’s (A), Lewy body (L), Vascular (V), Parkinson’s (P), Mixed (M) or not recorded (NR). Suggest patients recorded as ND are reviewed as to why on an antipsychotic as may have dementia.
3. Antipsychotic codes: Risperidone (R), olanzapine (O), quetiapine (Q), aripiprazole(A), haloperidol (H), if another drug please name in full.
4. Record as either year then month (YY/MM) or not recorded (NR).
5. Record as either year then month (YY/MM) or started recently (SR) or not recorded (NR).
6. Record the date or NA for ‘not applicable’.
7. If secondary care are only reviewing the patient to assess the ongoing benefits of prescribing a cholinesterase inhibitor (e.g. donepezil) to slow down cognitive decline, the antipsychotic should be reviewed by the GP.

2.6 Prescribing antipsychotics for people with dementia: An intial assessment form for GPs

The following document is available as an amendable Word document (Attachment 11) on the PrescQIPP website:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Standards

1. The clinical indications/target symptoms should be identified and clearly documented in the clinical records.
2. Before prescribing antipsychotic medication for BPSD (behavioural and psychological symptoms in dementia), likely factors that may generate, aggravate or improve such behaviours should be fully explored and documented in the clinical notes.
3. The potential risks and benefits of antipsychotic medication should be considered and documented by the clinical team prior to initiation.
4. The potential risks and benefits of antipsychotic medication should be discussed with the patient and/or carer(s), prior to initiation. These discussions should also include an explanation of the 'off-licence' nature of the treatments where risperidone is not used, and where risperidone may be used for longer than 6 weeks. A record of these discussions should be made in the clinical notes.
5. Wherever possible antipsychotic treatment should only commence if there is a recent ECG showing normal QTc interval. Similarly, baseline FBC, LFTs, U&Es and TFTs should be available. If baseline tests are not done there should be a full explanation in the clinical notes of the reason for this.
6. Medication should be regularly reviewed using the 'Prescribing antipsychotics for people with dementia medication review proforma', and filed/documented in the clinical records. The medication review should take account of therapeutic response and possible adverse effects. Initial review should be within a maximum 6 weeks from initial prescription and then as a minimum 3 monthly.

Patient name			
Patient date of birth		**Date of assessment**	
Practice			
GP			

Patient's sub-type of dementia (ICD-10 category) and clinician impression of severity of dementia

ICD 10 code	Dementia sub-type	Mild	Moderate	Severe

Prescribing antipsychotics for people with dementia: Initial assessment for GPs

Clinical indications/target symptoms

Please record below all the clinical indications for the current antipsychotic medication(s) in this patient. Please tick all that apply –with details if required.

Indication	Tick	Details if required
Known psychotic illness such as schizophrenia, bipolar disorder, psychotic depression		
Evident or assumed psychotic symptoms (delusions/hallucinations/paranoia/ suspiciousness not due to known psychiatric illness as in the previous box)		
Depression/low mood		
Disturbed sleep		
Fear/anxiety		
Agitation		
Distress		
Verbal aggression		
Physical aggression		
Disinhibited behaviour (e.g. removing clothes)		
Resisting help with activities of daily living such as hygiene, eating, drinking, dressing, etc.		
Wandering		
Other* Please specify		

Have the following potential underlying causes of BPSD (behavioural and psychological symptoms in dementia) been considered and treated if required? Tick all that apply and supply any relevant information.

Potential underlying cause	Tick	Relevant information
Depression		
Anxiety		
Pain		
Side effects of current medication		
Physical illness (constipation, UTI, chest infections, heart failure, etc)		
Other cause(s) * Please specify		

	Yes	No
Has there been referral to the guidelines flowchart on responding to behaviours that challenge (BPSD) in older people and those with dementia? See page 26 or Attachment 11 of PrescQIPP toolkit '[Reducing antipsychotic prescribing in people with dementia]'.		

Have any of the following non-pharmacological interventions been tried before an antipsychotic was prescribed? Please tick all that apply and supply any relevant information.

Non-pharmacological intervention	Tick	Relevant information
Engagement in social/personal activities		
Changes to staff approach (e.g. behavioural approach, distraction techniques)		
Changes to the environment (e.g. lighting, TV, availability of quiet areas, orientation aids)		

Patient name: Patient date of birth:

Prescribing antipsychotics for people with dementia: Initial assessment for GPs

Non-pharmacological intervention	Tick	Relevant information
'Watchful waiting'/monitoring		
Other approaches (e.g. reminiscence therapy, aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal assisted therapy, massage)		
Other * Please specify		

Risk/benefit analysis regarding antipsychotic medication (severity of BPSD vs side effects, risk of stroke, etc.)

Risk	Risk present – please detail	No evidence risk
Cardiovascular risk based on PMH of hypertension/diabetes/previous CVA or TIA		
Metabolic side effects based on PMH of obesity/diabetes/lipid profile		
Current physical health – robust/frail		
Other risk * Please specify		

	Yes	No
Risks and benefits regarding antipsychotic medication discussed with patient or carer?		
Medication information leaflets given to patient or carer?		
Written informed consent obtained from the patient?		
Discussion with and approval of the carer(s) documented?		
ECG within normal limits for QTc interval?		
Baseline FBC, LFTs U&Es and TFTs reviewed and not precluding prescription?		

On balance the decision to prescribe was made in light of the patient's presentation, symptomatology and risk to self or others.

Medication prescribed	
Dose	

This prescription should be reviewed within a maximum 6 weeks from initial prescription and then as a minimum 3 monthly.

Date of next scheduled review	
Assessment completed by (name of prescribing doctor	
Signature	
Date	

Patient name:

Patient date of birth:

2.7 Prescribing antipsychotics for people with dementia: Medication review for GPs

This form is available as an amendable Word document (Attachment 12) on the PrescQIPP website: http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Patient name			
Patient date of birth		Date of assessment	
Practice			
GP			

Date antipsychotic initially commenced		Antipsychotic prescribed	
Dose of antipsychotic currently prescribed		Date of last antipsychotic review(s) – if applicable	

Therapeutic response?	Yes		No	
Please specify improvements noted				

Adverse events	Yes - please detail	No
Falls		
Sedation		
Low blood pressure		
Chest infection		
Anticholinergic side effects (e.g. constipation, blurred vision, urine retention, dry mouth)		
Extra-pyramidal side-effects/mobility		
Other cause(s) * Please specify		

On balance the decision to continue with antipsychotic prescription was made in light of the patient's presentation, symptomatology and risk to self or others?	Yes	No
Any dose or drug changes? Please specify		
Non-drug intervention(s). Please specify		

This prescription should be reviewed within a maximum 6 weeks from initial prescription and then as a minimum 3 monthly.

Date of next scheduled review	
Review completed by (name of prescribing doctor)	
Signature	
Date	

2.8 Carer information leaflet

This leaflet is available as an adaptable Word document (Attachment 13) on the PrescQIPP website: http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

This carer information leaflet for you to adapt. Please ensure that you customise the text highlighted in yellow so that the information is appropriate.

Insert practice header, print to practice headed paper or type out the address below

[Date]

Carer information leaflet: Reducing or stopping antipsychotics medication in people living with dementia

There is evidence that suggests some medicines used to treat behavioural problems in people with dementia can have some serious side-effects. These include increasing the risk of the person having a stroke or falling. These medicines are called antipsychotics. There is also evidence that many behavioural problems disappear or become less troublesome over time, even without medication.

It has been decided by [**insert name of practice**] that most patients being prescribed an antipsychotic for behavioural problems should have this medicine reduced or stopped to see if it is still needed. It is our intention to try and stop prescribing the antipsychotic in approximately [**add time scale, e.g. 'one week's time'**]. If you have any concerns, please do not hesitate to contact the practice for advice.

Practice details	[Add number]

Clinical trials have shown that when stopping medication, even if the person was taking an inactive tablet (placebo), some carers think they see a worsening of behaviour. This may be due to the behavioural problems returning or a heightened sensitivity to any unwanted behaviour.

To help properly assess whether behaviour has significantly changed after the medicine is reduced or stopped we would like you to complete a diary, starting one week before the medication is reduced or stopped. A diary sheet has been designed for you to record on it the types of behavioural problems you are concerned about and how troublesome they are each day.

Once the medication is reduced or stopped, please keep recording any behavioural problems for the next 7 days. If there is a sudden worsening of behaviour that you feel is unmanageable then please call the practice to discuss your concerns.

We may agree to restart medication so you need to have a supply of a suitable medicine, just in case. Even if a medicine is restarted for behavioural problems, the intention is to regularly stop the medicine to assess its ongoing benefit.

If you feel that once stopped the antipsychotic is no longer needed then there is no need to let the practice know. A review can always be arranged if any difficult behavioural problems return.

Please take any unwanted medicines back to your community pharmacy or dispensing doctor for safe disposal.

Yours sincerely

Dr [Name] and partners

2.9 Example of a completed behavioural symptom recording form for people living with dementia

A blank copy of this form (Attachment 14) is available from the PrescQIPP website:
http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Behavioural symptom recording form for people living with dementia – to be completed by carer

- Describe the behavioural symptom(s) that concern you as a carer in the first column.
- At the end of each day, put the appropriate code in the column and make a comment if you wish, continuing on the back of the form if needs be.
- **Start 7 days before the medication is reduced or stopped and continue until 7 days after the medication is stopped.**
- Ideally the same person should complete the form each day.
- Use an additional form if necessary.

Column codes

A = Not a problem today B = A problem but manageable C = Finding it difficult to cope

Date medication reduced (if appropriate)		**Date medication stopped**	

Symptoms	**Date**													
	16/02	17/02	18/02	19/02	20/02	21/02	22/02	23/02	24/02	25/02	26/02	27/02	28/02	29/02
Hitting out when trying to wash and dress him.	A	B	A	A	B	B	A	B	B	A	A	A	B	A
Shouting loudly and unexpectedly for no apparent reason.	A	A	A	A	B	A	A	A	B	B	A	A	B	A

Date	**Comment**
17.02	Agitated after breakfast when washed but calmed down later.
19.02	Really calm today.
20.02	Dad was discovered to have a temperature and once given some paracetamol he calmed down.
23.02	Still on regular paracetamol
24.02	Paracetamol stopped after lunch and temperature stayed normal. More agitated than normal though.
26.02	Really calm today and more alert but calm.
28.02	A bad day today but manageable.

2.10 Example of an ABC chart

A blank copy of this form (Attachment 15) is available from the PrescQIPP website: http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

ABC chart

The ABC chart can be used to record behavioural concerns.

'A' stands for antecedents, that is, what occurs immediately before the behaviour you observe and can include any triggers, signs of distress or environmental information.

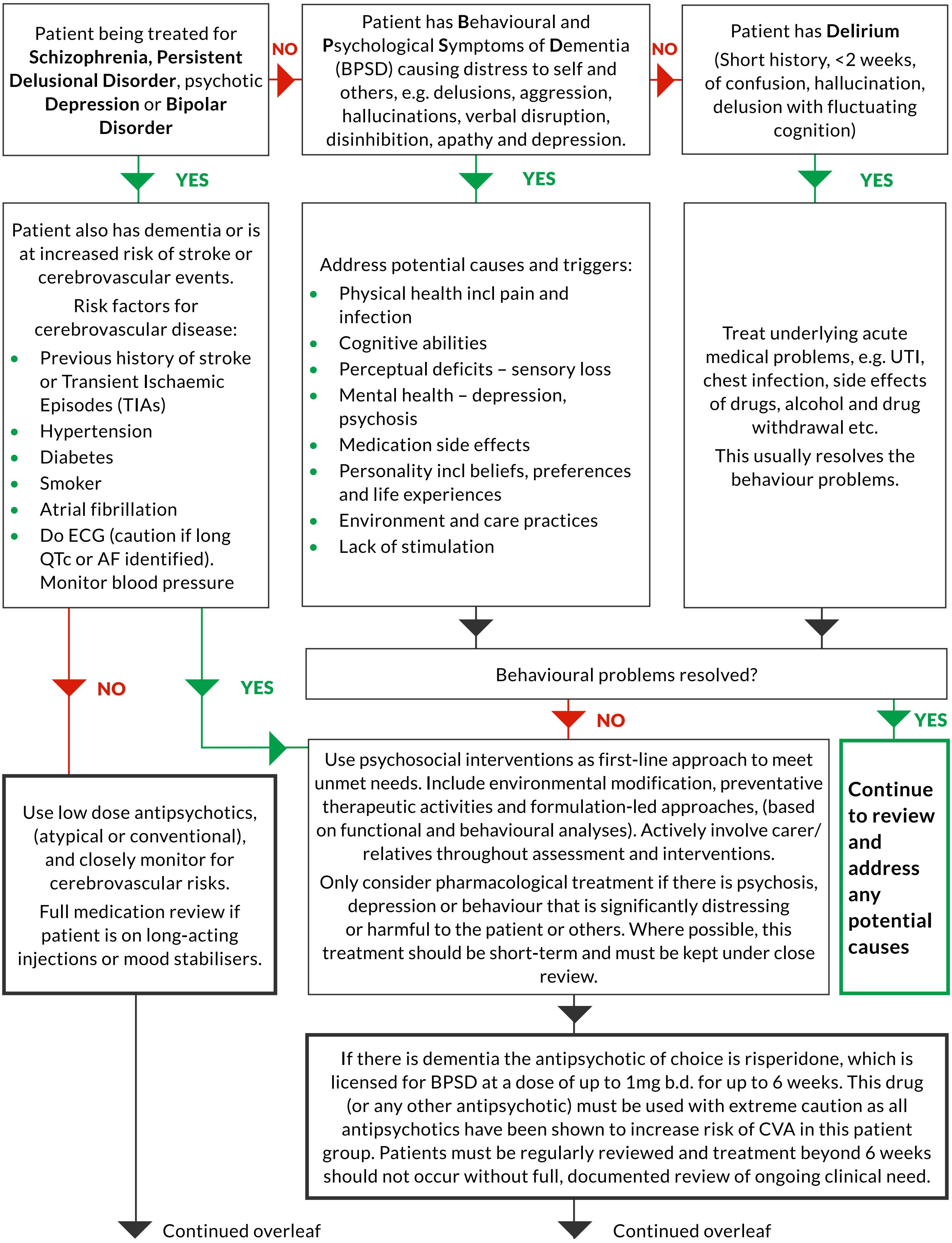
'B' refers to the behaviour itself and is a description of what actually happened or what the behaviour 'looked' like.

'C' refers to the consequences of the behaviour, or what happened immediately after the behaviour and can include information regarding other people's responses to the behaviour and the eventual outcome for the individual. It can also be a good idea to keep track of where and when the behaviour occurred to assist in identifying any patterns.

Date	Time	Antecedents	Behaviour	Consequences	Other information
Friday 6th December 2013	7.30am	Whilst giving her personal care	Mrs E started to shout and wave her hands at the carer	She stopped shouting and waving her arms when her regular carer came into the room and started to attend to her	

2.11 Responding to behaviours that challenge (BPSD) in older people and those with dementia

(Does not cover rapid tranquillisation of acutely disturbed)



Patient being treated for **Schizophrenia, Persistent Delusional Disorder**, psychotic **Depression** or **Bipolar Disorder**

Patient has **B**ehavioural and **P**sychological **S**ymptoms of **D**ementia (BPSD) causing distress to self and others, e.g. delusions, aggression, hallucinations, verbal disruption, disinhibition, apathy and depression.

Patient has **Delirium**

(Short history, <2 weeks, of confusion, hallucination, delusion with fluctuating cognition)

Patient also has dementia or is at increased risk of stroke or cerebrovascular events.

Risk factors for cerebrovascular disease:

- Previous history of stroke or Transient Ischaemic Episodes (TIAs)
- Hypertension
- Diabetes
- Smoker
- Atrial fibrillation
- Do ECG (caution if long QTc or AF identified). Monitor blood pressure

Address potential causes and triggers:

- Physical health incl pain and infection
- Cognitive abilities
- Perceptual deficits – sensory loss
- Mental health – depression, psychosis
- Medication side effects
- Personality incl beliefs, preferences and life experiences
- Environment and care practices
- Lack of stimulation

Treat underlying acute medical problems, e.g. UTI, chest infection, side effects of drugs, alcohol and drug withdrawal etc.

This usually resolves the behaviour problems.

Behavioural problems resolved?

Use low dose antipsychotics, (atypical or conventional), and closely monitor for cerebrovascular risks.

Full medication review if patient is on long-acting injections or mood stabilisers.

Use psychosocial interventions as first-line approach to meet unmet needs. Include environmental modification, preventative therapeutic activities and formulation-led approaches, (based on functional and behavioural analyses). Actively involve carer/relatives throughout assessment and interventions.

Only consider pharmacological treatment if there is psychosis, depression or behaviour that is significantly distressing or harmful to the patient or others. Where possible, this treatment should be short-term and must be kept under close review.

Continue to review and address any potential causes

If there is dementia the antipsychotic of choice is risperidone, which is licensed for BPSD at a dose of up to 1mg b.d. for up to 6 weeks. This drug (or any other antipsychotic) must be used with extreme caution as all antipsychotics have been shown to increase risk of CVA in this patient group. Patients must be regularly reviewed and treatment beyond 6 weeks should not occur without full, documented review of ongoing clinical need.

Continued overleaf

Continued overleaf

If antipsychotic treatment is indicated

Start doses low (e.g. half adult initial dose) and increase slowly (e.g. every 2-4 days). Review regularly and withdraw if behaviour resolves. Stopping should always be considered and discussed after 6 weeks in order to make a full assessment of ongoing need and benefit. Monitor for side effects and for potential worsening of cognitive function, which is possible with all antipsychotics. Also note that use of antipsychotics in the elderly increases risk of pneumonia by up to 60%.

To reduce CVA risk, ensure patient remains well hydrated and maintains mobility (where possible).

Medication options

Behavioural disturbances: Cautiously consider **risperidone** as first-line medication for persistent aggression in dementia that is not responsive to non-drug approaches and where there is risk of harm to the patient or others. Starting dose is 0.25mg b.d. adjusted on alternate days to not more than 1mg b.d.

Other antipsychotics should be avoided wherever possible but may be considered in low doses. Cholinesterase inhibitors, memantine and trazodone are also potential treatment options (depending on local guidelines/ policy). Carbamazepine has demonstrated efficacy, but valproate should be avoided as it is poorly tolerated. Benzodiazepines should be avoided other than in extreme cases. Use short-acting lorazepam or oxazepam that are less likely to accumulate, but review regularly and monitor closely for worsening confusion, ataxia and risk of falls.

Depression: Consider antidepressant medication if clinically depressed. Citalopram is first choice if not contraindicated. Sertraline, mirtazapine and trazodone are alternatives. All may help restlessness and agitation.

Anxiety: Should respond to an antidepressant longer-term. Use short-term benzodiazepines or antipsychotics only as a last resort in response to acute, severe agitation, but keep under close review.

Poor sleep: Improve sleep hygiene. If needed try short-term use of zolpidem or zopiclone.

In the event of continuing problems, telephone advice can be obtained from the local mental health team.

Note

In the treatment of BPSD, the use of an antipsychotic, (other than risperidone), is an ‘off licence’ use of the medicine.

Useful website addresses

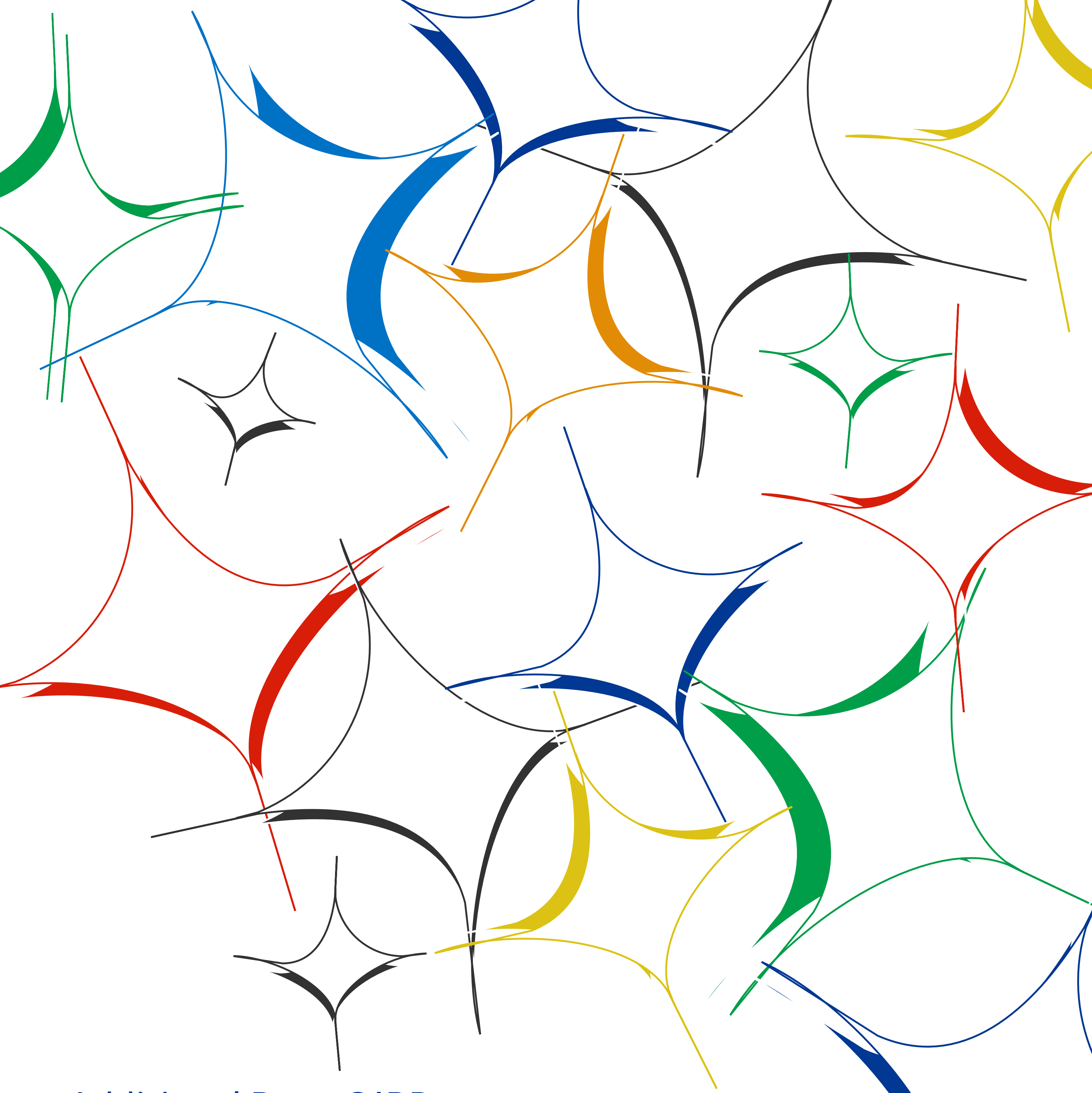
- The Alzheimer's Society has produced a best practice guide to optimise the treatment and care of the behavioural and psychological symptoms of dementia.
  http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1163
- The Alzheimer's Societies information on drugs used to relieve behavioural and psychological symptoms in dementia.
  http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=110
- Social Care Institute for Excellence (SCIE) has a dementia gateway for people who work with people with dementia.
  http://www.scie.org.uk/publications/dementia/index.asp
- Dementia UK is a charity committed to improving quality of life for all people affected by dementia.
  http://www.dementiauk.org
- The National Prescribing Centre (NPC) has produced a presentation with commentary on antipsychotic prescribing in dementia.
  http://www.npc.nhs.uk/qipp/qipp_pod/antipsychotics_recorded_commentary.php

Acknowledgements

A number of prescribing committees in Sussex and specialist groups in the Sussex Partnership NHS Foundation Trust contributed to the development of the original resource pack.

References

1. International Psychogeriatric Association. BPSD: Introduction to behavioural and psychological symptoms of dementia, 2002. Accessed online 03/01/14 and available at: www.ipa-online.org
2. McShane RH. What are the syndromes of behavioural and psychological symptoms of dementia? International Psychogeriatric 2000; 12 (suppl1): 147 - 53. Accessed 03/01/14.
3. Optimising treatment and care for people with behavioural and psychological symptoms of dementia. A best practice guide for health and social care professionals. Alzheimer's Society, 2011. Accessed online 22/01/14 and available at: www.alzheimer's.org.uk/bpsdguide
4. Dementia. Supporting people with dementia and their carers in health and social care. NICE clinical guidance 42 (2006 modified 2012). Accessed online 22/01/14 and available at: www.guidance.nice.uk/cg42
5. Banerjee S. The use of antipsychotic medication for people with dementia: Time for action. Department of Health 2009. Accessed online 05/05/14 and available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf
6. Guidance on the management of pain in older people. Age Ageing 2013; (suppl 1): i1 –i57. Accessed 07/05/14 and available at: http://ageing.oxfordjournals.org/content/42/suppl_1.toc
7. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. Journal of American Medical Directors Association 2003; 4: 9-15.
8. Guidelines for discontinuation and reduction of antipsychotics in dementia patients in the community. NHS London, April 2012, updated September 2013. Accessed 25/01/14 and available at: http://www.medicinesresources.nhs.uk/en/Communities/NHS/SPS-E-and-SE-England/Meds-use-and-safety/Service-deliv-and-devel/Mental-health/Antipsychotic-Medicines-Audit-and-Reduction-Tool-Vs1/ (Appendix 7)



Additional PrescQIPP resources

Implementation resources

Available for download at:

http://www.prescqipp.info/resources/viewcategory/241-reducing-antipsychotic-prescribing-in-dementia-toolkit

Information prepared by Cherise Howson, PrescQIPP NHS Programme, May 2014 and reviewed by Katie Smith, East Anglia Medicines Information Service, June 2014.

Non-subscriber publication October 2014.