

Optimising treatment and care
for people with behavioural and
psychological symptoms of dementia

A best practice guide for health
and social care professionals



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ABOUT THIS GUIDE

This best practice guide has been developed in consultation with an advisory group of leading clinicians specialising in dementia. It aims to provide evidence-based support, advice and resources to a wide range of health and social care professionals caring for people with dementia who have behavioural and psychological symptoms. It has been designed to be a practical, informative tool, with an emphasis on alternatives to drug treatment.

These best practice principles and supporting materials are intended to be applicable to all professional groups, except in acute general hospital settings. We hope they will be helpful to practitioners in environments where this aspect of clinical practice will increasingly come under scrutiny. For practitioners who are specialists or who require information beyond the scope of this document, links to additional resources are provided (see 'Resources' on page 19/20).

'Getting prescribing right for people with dementia, who are among the most vulnerable in our society, is a clinical imperative. A proper assessment and a thorough understanding of the role of the array of interventions available for people with dementia is essential so the correct and safest treatment can be delivered. We hope that this guidance will help achieve that aim.'

Professor Alistair Burns,
National Clinical Director for Dementia in England,
National Health Service for England

'The potential serious adverse events associated with antipsychotics in people with dementia have become increasingly evident over the last decade. Achieving a change in prescribing practice has been challenging because of the complex issues involved in the treatment of behavioural and psychological symptoms in people with dementia. The political imperative to reduce antipsychotic use has been extremely important, but it is vital that this is achieved within a context that enables better overall management and treatment of symptoms as well as responsible and safe prescribing of antipsychotics and other psychotropic drugs when indicated. We hope that this best practice guide provides a practical, evidence-based framework to support health and social care professionals to provide the best available treatment and care for people with dementia.'

Professor Clive Ballard,
Pro-Vice-Chancellor and Executive Dean,
University of Exeter Medical School

The advisory group was co-chaired by Professor Alistair Burns and Professor Clive Ballard. Dr Anne Corbett, Senior Lecturer in Dementia Research at the University of Exeter Medical School, led the development of the resource, with Alistair Burns and Clive Ballard, based upon the recommendations and feedback of the advisory group.

Advisory Group: Clive Ballard, Sube Banerjee, Nina Barnett, Donald Brechin, Dawn Brooker, Alistair Burns, Peter Connolly, Anne Corbett, Jane Fossey, Clive Holmes, Julian Hughes, Gill Livingston, Lisa Bayliss Pratt.

An e-learning package containing guidance and practice scenarios is now available on the British Medical Journal online education platform <http://learning.bmj.com/learning/home.html>

INTRODUCTION

This guide has been designed to support health and social care professionals to determine the best treatment and care for people experiencing behavioural and psychological symptoms of dementia (BPSD).

There are currently 800,000 people with dementia in the UK, approximately one third of whom live in care homes. People with dementia experience a range of symptoms. Some can affect their behaviour, others are personal, inner experiences. These include agitation, aggression, hallucinations and delusions. There are many ways of describing this varied group of symptoms. For clarity and convenience they are referred to throughout this guide as 'behavioural and psychological symptoms of dementia' or 'BPSD', an umbrella term devised by the International Psychogeriatric Association.

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 these symptoms at any one time. BPSD cause distress to the individual, add considerably to the stresses experienced by family and professional carers and can result in serious risks to the person and others. Many individuals experiencing these symptoms do not have the legal capacity to make informed decisions about their treatment. Care should therefore be taken to use this guide within the context of the Mental Capacity Act 2005.

Good practice recommendations, such as the NICE dementia guidelines, recommend psychosocial interventions as the first line approach and emphasise the importance of assessing medical conditions and pain, which often underpin the development of these symptoms. The value of not rushing into treatment is also important, as many people with BPSD will experience significant improvement or resolution of symptoms over a 4–6 week period.

In practice, pharmacological interventions, and in particular antipsychotic medication, are often used as a first line treatment. While atypical antipsychotics do confer modest benefits in treating aggression and psychosis over 6–12 weeks, they are associated with a number of major adverse outcomes and side-effects including sedation, parkinsonism, gait disturbance, dehydration, falls, chest infections, accelerated cognitive decline, stroke and death.

An audit carried out in 2009 reported that 180,000 people with dementia were receiving antipsychotic drugs, of which large numbers were considered unnecessary. A report indicated that this was leading to 1800 strokes and 1600 additional deaths each year in people with dementia. In a response to this inappropriate prescribing, the UK government launched a series of initiatives to encourage reductions in the use of these drugs. This approach has proven successful, with a 2012 audit indicating reductions of 40% nationwide. However, antipsychotics are still in use. It is critical that clinicians strive to use alternative treatment approaches and ensure they prescribe with informed caution in cases where antipsychotics are warranted.

Although there are many principles of good practice outlined in numerous guidelines, these documents are lengthy and often lack the practical detail required to enable implementation by clinicians.

This guide aims to provide a simple and practical pathway to enable the implementation of the principles outlined in best practice guidelines for the treatment of BPSD in everyday clinical settings. It has been designed to be used for reference where needed. It is not intended for use in acute general hospital settings.

90%
of people with dementia
will experience BPSD.

HOW TO USE THIS GUIDE

HOW TO USE THIS GUIDE

The guide follows a basic stepped care model based on a colour-coded traffic light system.

The traffic light colours represent:

PREVENTION

Green – No symptoms

Simple preventative measures

WATCHFUL WAITING

Amber – Mild or moderate symptoms

Low intensity, general interventions

SPECIFIC INTERVENTIONS ANTIPSYCHOTIC PRESCRIPTION

Red – Severe symptoms

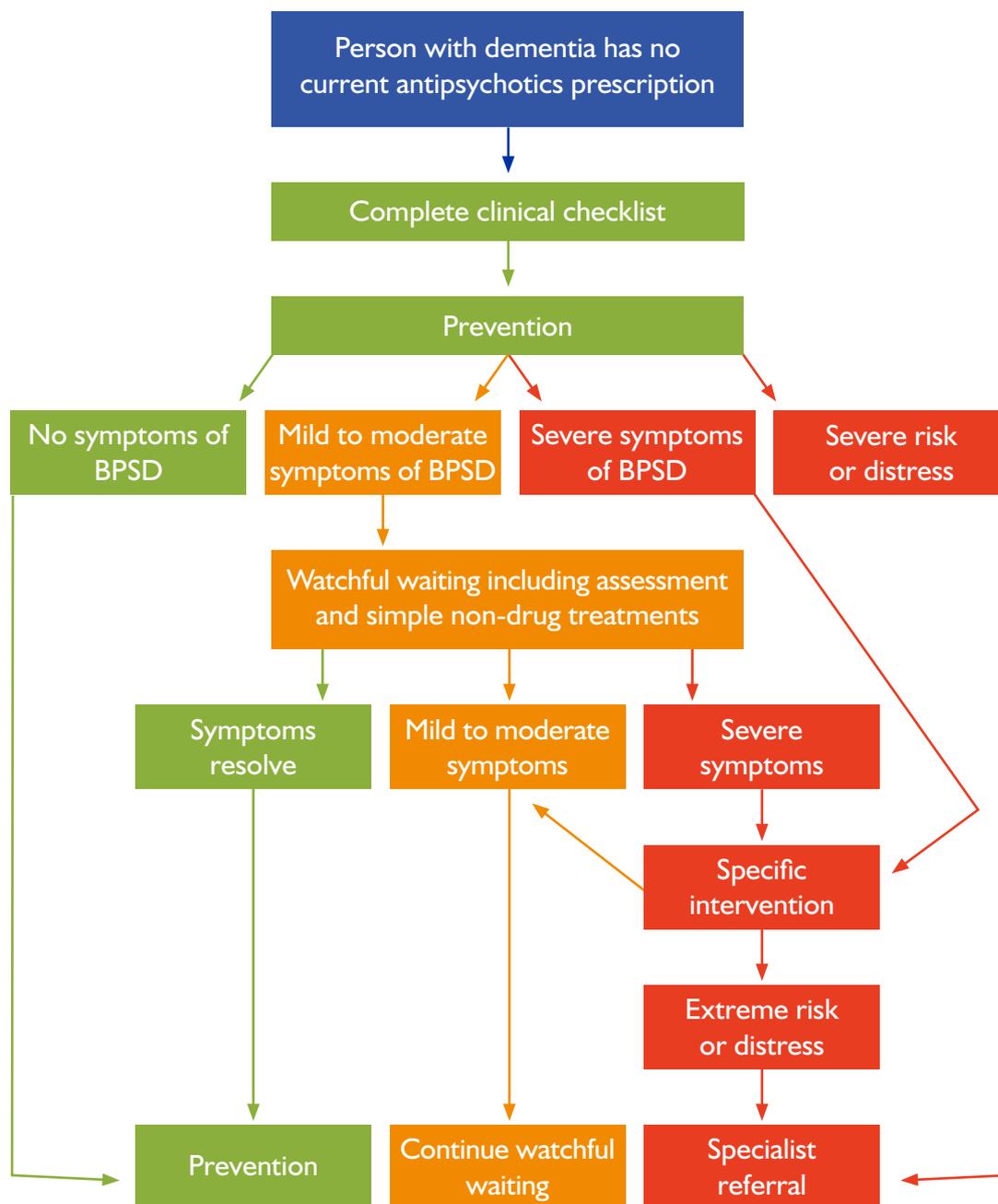
Specific interventions and guidance

for antipsychotic use

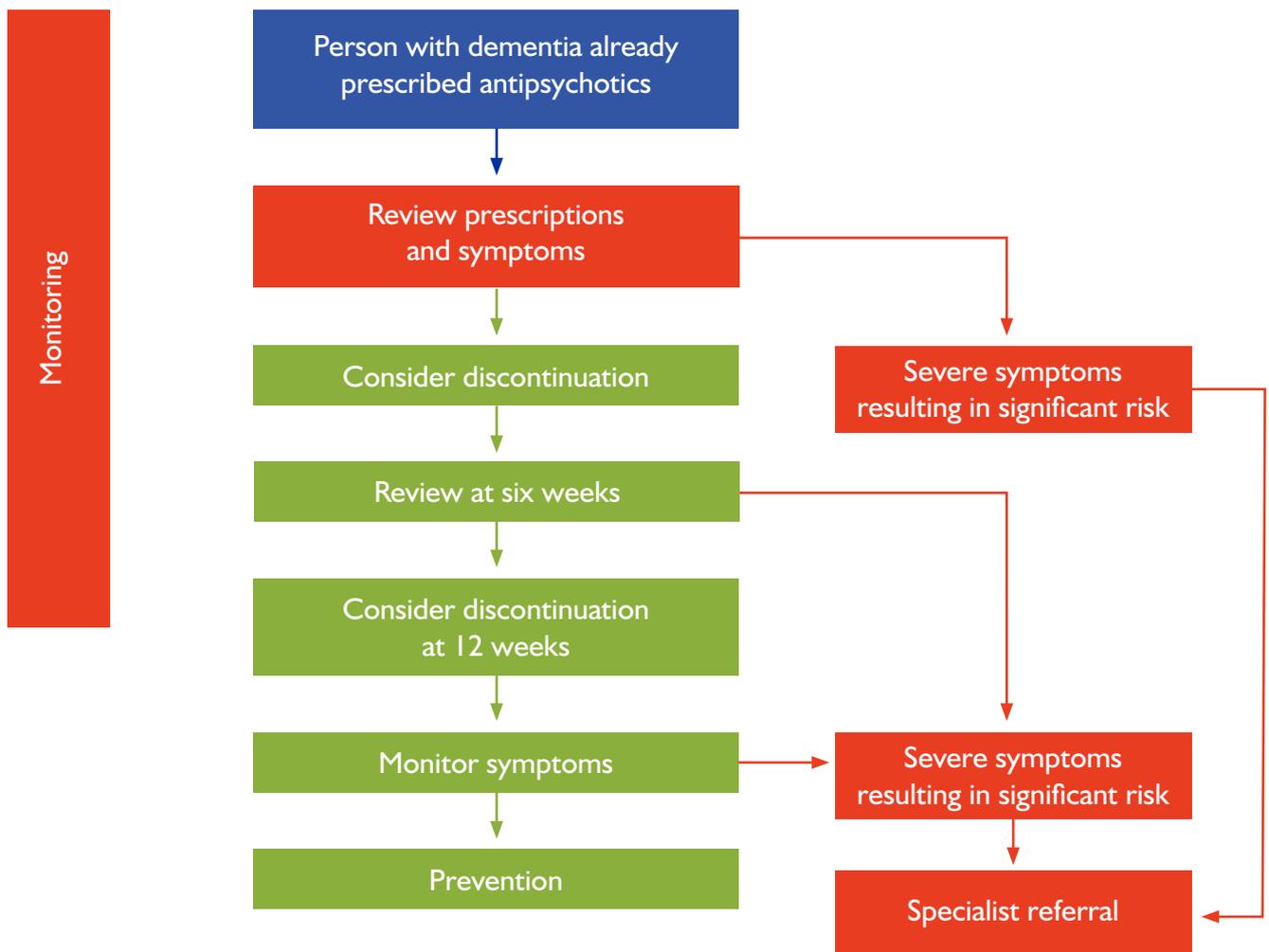
The two simple posters (on the following pages) can be used to help determine the best care and treatment for each person with dementia. Choose the relevant pathway depending on whether the person has already been prescribed antipsychotics or not. Guidance is colour coded. Additional charts and care planning resources are available in the online appendix <http://medicine.exeter.ac.uk/media/universityofexeter/medicalschool/documents/nhs-appendix.pdf>

20% of people in care homes are on an antipsychotic drug.

PATHWAY FOR A PERSON WHO DOES NOT HAVE A CURRENT ANTIPSYCHOTIC PRESCRIPTION



PATHWAY FOR A PERSON WHO HAS ALREADY BEEN PRESCRIBED ANTIPSYCHOTIC DRUGS



DECISION SUPPORT FOR TREATMENT IN SOMEONE RECEIVING AN ANTIPSYCHOTIC

The simple table below provides guidance on the most appropriate course of action based on the symptoms experienced by a person with dementia. This advice is based on a full review of the evidence and clinical experience of the authors.

Score	Symptoms	Action
0	No symptoms.	Discontinue antipsychotic. Commence non-drug Watchful Waiting.
1	Infrequent, mild symptoms.	Discontinue antipsychotic with clear non-drug treatment plan. Assess for pain and consider use of paracetamol as first-line pharmacological treatment.
2	Occasional outbursts of non-aggressive symptoms.	Consider discontinuation with non-drug treatment plan. Consider alternative pharmacological options if clinically indicated (not suitable for psychosis).
3	Regular outbursts of non-aggressive agitation, resistance to care, occasional aggressive symptoms.	Consider discontinuation followed by use of alternative pharmacological options. Discontinuation should be attempted twice before considering longer term antipsychotic prescription.
4	Shouting, aggression, risk to others.	Refer to Specialist.

PREVENTION

PREVENTION GUIDANCE

People with dementia often experience behavioural and psychological symptoms such as agitation, aggression and psychosis. There are a number of simple approaches to treatment and care that can help reduce the chance of these symptoms developing.

This section provides practical guidance for creating an effective care plan for a person with dementia. This guidance is based on the principles of person-centred care.

Medical review

A thorough medical review is essential to detect any general health problems that could impact on the person's quality of life, wellbeing or other symptoms. In particular, pain can be a major trigger for agitation and aggression, and infections (eg urinary tract infection) can increase a broad range of BPSD. Other key triggers include dehydration, constipation and malnourishment or hunger. A record should also be kept of any clinically significant behavioural symptoms.

For each person with dementia complete:

- a medical review (including medication review)
- the checklist for specific clinically significant symptoms (see prevention checklist in appendix <http://medicine.exeter.ac.uk/media/universityofexeter/medicalschooldocuments/nhs-appendix.pdf>).

Understanding of dementia

It is important that all care staff are aware of and understand the needs of a person with dementia, including aspects of person-centred care. Dementia affects people in different ways, causing a broad range of symptoms. This means that there is not a 'one-size-fits-all' care strategy. Different types of dementia may also require different approaches to treatment, depending on the symptoms and types of drugs that are suitable for that type of dementia.

It is also important to recognise that behavioural and psychological symptoms are not 'bad behaviour' on the part of the person. These symptoms are often associated with chemical changes in the brain, or are caused by social and environmental triggers. Simple adjustments to social interactions and environment can make a difference.

Recognition of triggers and early signs

Recognition of triggers and early signs that may precede behavioural and psychological symptoms is crucial. In most cases developing simple approaches to address these early signs can help prevent symptoms from developing at all. Key signs to look out for are:

- pain, discomfort, malnourishment, dehydration, boredom and physical illness – these are very common triggers which are often overlooked
- stress, irritability, mood disturbance and suspiciousness
- increased levels of distress
- early signs may be noticed at certain times of the day and may indicate a specific trigger
- although not the most common trigger, it is important to be aware of any signs of abuse or neglect.

Pain is one of the most common causes of BPSD.

Pharmacological treatments

Acetylcholinesterase inhibitors (Aricept, Exelon, Reminyl) and memantine are licensed for mild-moderate and moderate-severe Alzheimer's disease, respectively. There is some evidence that both groups may delay the onset of BPSD, providing additional benefit to using these currently available treatment options.

Person-centred care

This approach to care is based on understanding the person's history and experiences (their work, life, hobbies, family, environment and religious beliefs), their likes and dislikes, and taking their perspective into account. It is also important to ensure that the person has the opportunity for human contact and warm relationships with others.*

Key questions to ask are:

- Is the person treated with dignity and respect?
- Do you know about their history, lifestyle, culture and preferences?
- Do the carers try to see the situation from the perspective of the person with dementia?
- Does the person have the opportunity for relationships with others?
- Does the person have the opportunity for stimulation and enjoyment?
- Has the person's family or carer been consulted?
- Does the person's care plan reflect their communication needs and abilities?

More detailed approaches to person-centred care are outlined in **watchful waiting guidance**. Staff training in person-centred care can be helpful.

Physical environment

It is important to consider the person's environment and how it might affect them. Key questions to ask are:

- If the person is being cared for in a bed or chair, are they comfortable and free of pressure sores?
- Is the TV or radio playing something that the person can relate to and enjoy?
- If the person is mobile, can they move around freely and have access to outside space?
- Does the person recognise the environment as home? Does it contain things to help them feel at home?
- Could assistive technology be used to improve freedom or safety?
- Is the person wearing the correct glasses, and are they clean?
- Is their hearing aid turned on and working correctly?
- Is it too hot or too cold?
- Is the person hungry? People may forget to eat.

Sudden emergence of BPSD often has a physical trigger. Longer onset emergence can be linked to depression.

*Clinical trials have shown significant benefit to antipsychotic use and behavioural symptoms following interventions that focus on person-centred care.

WATCHFUL
WAITING

FIRST LINE INTERVENTIONS, ONGOING ASSESSMENT AND WATCHFUL WAITING GUIDANCE

Behavioural and psychological symptoms of dementia often disappear over four weeks without the need for medication. It is important to identify and address any triggers or unmet needs that may have caused the symptoms. Simple changes in treatment and care can avoid the use of antipsychotic drugs in people with dementia.

This section provides guidance and charts for first line interventions and an ongoing assessment protocol called 'watchful waiting.' This is an important step in person-centred care, and should be tried with all patients unless there is extreme distress or risk.

Medical review

Any person showing onset of BPSD should receive a full medical review.

Person-centred care

The first approach for behavioural and psychological symptoms is to develop a simple Clinical Care Plan for simple non-drug treatments based on person-centred care. It is important to design the plan around the person's needs, abilities and interests.*

Key considerations are:

- Do the carers understand how the person is feeling? Are plans based on their point of view?
- What are the person's preferences and opinions?
- Consider the person's relationships with others. How are these supported?
- Do the carers help the person to feel socially confident and not alone?
- How is the person included in conversations and care?

- How are they shown respect, warmth and acceptance?
- Are the person's fears recognised and addressed?
- What are their life history, culture and interests?
- Do they have any sensory problems (e.g. with hearing or sight)?
- Do they have communication problems?
- Do they have any physical needs or mobility issues?
- Have carers considered ways to help them with perceptual or memory problems?

Working with carers or care staff to develop a specific person-centred care plan and activity programme can make a substantial difference.

Consult with the family

It is essential to discuss the person's symptoms and possible treatments with their family or carer. They may be able to shed light on the reasons for their symptoms and ways to engage them in activities.

Soothing and creative therapies

Although there is not necessarily a robust evidence base to support them, aromatherapy and massage can help to soothe, as can warm towels or smells of cooking, or having one's hair brushed or a manicure. Music can help improve a person's mood. Music from the past can bring back good memories. Singing and dancing can energise people and lift spirits. It may be helpful to try these if they are available in the care setting.

* RCTs have shown significant benefit to antipsychotic use and behavioural symptoms following interventions that focus on person-centred care.

Simple non-drug treatments

These might include:

- developing a life story book
- frequent, short conversations (as little as 30 seconds has proven effective)
- using personal care as an opportunity for positive social interaction.**

Sleep hygiene

It may help to consider:

- reducing daytime napping
- increasing activities during the day
- agreeing realistic expectations for sleep duration.

Just 60 minutes of pleasant activities each week improves behaviour and other symptoms.***

** RCT evidence shows benefit to behaviour with social interaction.

*** A large RCT has shown that people benefit from receiving just 60 minutes of pleasant activities each week.

SPECIFIC INTERVENTIONS

SPECIFIC INTERVENTIONS GUIDANCE

If behavioural and psychological symptoms have not improved with **watchful waiting**, it is appropriate to try a specific intervention that is tailored to the person.

This section provides guidance on specific psychological and pharmacological approaches. Psychological approaches should be used first unless there is extreme risk or distress.

Pharmacological options are based on the best available evidence and should be used within an overall care plan tailored to the person. All antipsychotic prescriptions should be reviewed after 12 weeks.

Medical review

All people with persistent BPSD should receive a full medical review.

Psychosocial interventions

Psychosocial interventions are more tailored, systematic approaches to person-centred care (than those outlined earlier in watchful waiting).

The following steps should be taken to develop a specific intervention care plan:

- Complete medical and mental health review using resources in **online appendix** <http://medicine.exeter.ac.uk/media/universityofexeter/medicalschooldocuments/nhs-appendix.pdf>
- Consider all aspects of person-centred care (see **watchful waiting guidance in online appendix**)
- Consult with family or carers on the best approach
- Design specific interventions (the brief and simple approaches below have been shown to be effective and can be administered by care staff with support from any clinician)
- Consider whether care staff require specific dementia training (person-centred care training for staff can reduce antipsychotic use and improve agitation).

Improving social interactions

Brief psychosocial therapies help to engage people in ways that they find interesting and enjoyable. These should generally include 10–30 minutes of daily one-to-one conversation or activity based on the person's interests, hobbies, history and ability, and feedback from their carer and/or family.

Promoting positive activities and exercise

Evidence indicates that exercise and promotion of pleasant events improves physical function, cognition and mood. A range of ideas for this are presented in the Seattle Protocols (see resources on page 20).

Some options include:

- exercises – gentle stretching, strength training, balance and endurance
- pleasant activities – build an understanding of the person's likes and interests to engage them in the exercise or activity
- problem-solving – asking the person to suggest ways to make their exercise activity more enjoyable or effective.

Personalised activities

Create a menu of pleasant activities that are tailored to the person and that can be completed with care staff.*

For example:

- looking at photographs or pictures from their past
- playing specific games or doing puzzles
- creating a scrap book or similar simple craft project
- going for a walk.

Specialist psychosocial interventions

There is good evidence for the value of specific interventions delivered by a clinical psychologist or equivalent health professional. Appropriate approaches include the Antecedent Behaviour Consequence (ABC) approach to develop individualised intervention plans. These approaches are effective but require specialist referral.

* Clinical trials show improvement in agitation with individualised activities.

Pharmacological treatments

The following pharmacological approaches could be attempted if appropriate for the symptoms.

Depression

The effectiveness of pharmacological treatment for depression in people with dementia has not been established. Evidence shows positive events and exercise are effective for mild to moderate depression. For severe depression pharmacological treatment may be appropriate.

In the absence of other evidence, widely used antidepressants are citalopram and mirtazapine. Caution should be used with citalopram at >20mg/day due to QTc prolongation.

Sleep disturbance

When sleep disturbance is the main problem and sleep hygiene measures have failed, short term treatment (4 weeks) with a hypnotic such as zopiclone 3.75 mg/day (max 7.5 mg/day) or zolpidem (5 mg/day) can be helpful. However, this is only supported by anecdotal evidence.*

Agitation, aggression and psychosis

Where all other specific interventions have been unsuccessful and symptoms are causing extreme distress or risk, a trial of pharmacological treatments specifically targeted at behavioural and psychological symptoms may be attempted. There is only very preliminary evidence for the benefit of non-antipsychotic drugs although they may have a better safety profile.

Citalopram has shown benefit to agitation in a recent RCT but authors urge caution due to QTc prolongation and negative impact on cognition following doses of 30mg. However, this option is probably less harmful than an antipsychotic.

A recent IPA consensus panel recommended analgesics and citalopram as the best pharmacological options. Analgesic should be based on assessment of pain, Paracetamol 1g (up to 4 times a day).**

Whilst there are a number of emerging candidate treatments with preliminary evidence, this is not strong enough for recommendations for practice.

Alzheimer's treatments

There is evidence that acetylcholinesterase inhibitors (donepezil, rivastigmine, galantamine) and memantine may improve cognition in people with agitation. Evidence indicates that acetylcholinesterase inhibitors do not specifically improve agitation.

Psychosis

Whilst there are no licensed treatments for psychosis in Alzheimer's disease there is evidence of modest benefit with some atypical antipsychotics. The best evidence is for risperidone at 1mg/day. There is no evidence of benefit to psychosis with any other pharmacological approach.

Antipsychotic

Risperidone is the only antipsychotic licensed for people with dementia. Licence indication states that risperidone should be used for no longer than six weeks before review or specialist referral. NICE guidance states similar principles but gives a maximum treatment time of 12 weeks. A cardiac risk assessment is recommended prior to starting a prescription.

- Start dose 0.25mg (250 micrograms) twice a day
- Minimum therapeutic dose 0.5mg (500 micrograms) twice a day
- Maximum dose 1mg twice a day***

It is important to work up to a therapeutically effective dose from a low starting dose.

Caution: antipsychotics should not be used in someone with Lewy Body Dementia (LBD) without specialist advice.

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.

Other pharmacological options (e.g. benzodiazepines) carry no evidence of benefit and may increase other adverse events such as falls.

ANTIPSYCHOTIC PRESCRIPTION

SPECIFIC INTERVENTIONS GUIDANCE

Antipsychotic drugs may be the most appropriate treatment option once other alternatives have failed. Antipsychotic drugs can cause severe side-effects.

Monitoring of symptoms is therefore extremely important. All prescriptions should be reviewed after six (recommended) or 12 weeks. Discontinuation after 12 weeks should be the default except in extreme circumstances.

This section provides guidance on monitoring and review of a person with an antipsychotic prescription.

This guidance should be used when reviewing prescriptions and used to complete the **Review Chart** (available in the appendix online <http://medicine.exeter.ac.uk/media/universityofexeter/medicalschooldocuments/nhs-appendix.pdf>).

Discontinuation of antipsychotics

70% of people have no worsening of symptoms when antipsychotics are discontinued.

For those with worsening of symptoms the first four weeks are the most challenging but are often effectively managed with watchful waiting, preventing the need to restart antipsychotics. The risk of recurrence of behavioural and psychiatric symptoms after discontinuation may be more likely if:

- previous discontinuation has caused symptoms to return
- the person currently has severe symptoms.

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

Unless there is severe risk or extreme distress the recommended default management is to discontinue the antipsychotic and monitor/assess using watchful waiting or specific interventions.

If symptoms recur, at least two attempts should be made to discontinue antipsychotic prescription before moving to longer term treatment. If symptoms remain severe (with associated severe risk and/or distress) and further treatment with antipsychotics is considered clinically necessary, a referral to specialist services is advised. For ongoing safety monitoring refer to the **Monitoring Plan** (available in the online appendix <http://medicine.exeter.ac.uk/media/universityofexeter/medicalschooldocuments/nhs-appendix.pdf>).

Antipsychotic drugs are known to be harmful and can have severe side-effects. It is vital that any person prescribed these drugs is monitored for side-effects and progression of symptoms. This plan should be completed for each person with dementia when a prescription of antipsychotics is started.

Adverse effects of antipsychotic drugs

The most important adverse effects associated with antipsychotics are parkinsonism, falls, dehydration, chest infections, ankle oedema, deep vein thrombosis/pulmonary embolism, cardiac arrhythmia and stroke (highest risk in first four weeks of treatment).

Antipsychotics are also associated with increased mortality in the long term (often related to pneumonia and thrombo-embolic events) which can be caused by over-sedation and dehydration. Weekly monitoring of sedation, fluid intake and early indicators of chest infection is strongly recommended.

Caution: antipsychotics should not be used in someone with Lewy Body Dementia (LBD) without specialist advice.

RESOURCES

RESOURCES

A BMJ e-learning module for GPs on the management of behavioural symptoms is available through the BMJ online platform <http://learning.bmj.com/learning/home.html>

Assessment scales

A full range of assessment scales is available in *Assessment Scales in Old Age Psychiatry*, 2nd edition (2004) Editors: Alistair Burns, Brian Lawlor and Sarah Craig, Martin Dunitz: Taylor and Francis Group, London. Some of these scales will be available online free of charge but we recommend checking the copyright status before use.

Recommended scales for individual symptom types are:

- Behavioural symptoms and psychosis: Neuropsychiatric Inventory⁹
- Pain: Abbey Pain Scale¹⁰
- Depression: Cornell Depression Scale for Dementia¹¹

Best practice guidelines

Dementia (CG42): Assessment, management and support for people living with dementia and their carers. This will be updated Summer 2018 and will be available on the NICE website.

Good practice in prescribing medicines – guidance for doctors. General Medical Council. Available online at https://www.gmc-uk.org/guidance/ethical_guidance/14316.asp This document also includes guidance on off-licence prescribing.

British National Formulary. Available at www.bnf.org

Intervention protocols for non-drug treatments

The Seattle protocols: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518041/>

Simple Pleasures: A multilevel sensorimotor intervention for nursing home residents with dementia (1999) Linda L. Buettner. Available by emailing rth@uncg.edu

For more information on the Simple Pleasures intervention: <https://www.recreationtherapy.com/re-simp.htm>

Antecedent behaviour consequence (ABC) approach: http://www.specialconnections.ku.edu/?q=behavior_plans/functional_behavior_assessment/teacher_tools/antecedent_behavior_consequence_chart

Improving Wellbeing and Health for People with Dementia (WHELD). Training will shortly be available via the University of Exeter. <https://www.oxfordhealth.nhs.uk/research/making-a-difference/improving-wellbeing-and-health-for-people-with-dementia-wheld/>

Additional charts and Checklists

Supporting resources are available in an online appendix and download. These can be accessed at <http://medicine.exeter.ac.uk/media/universityofexeter/medicalschooldocuments/nhs-appendix.pdf>

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