NHS
East of England

Antipsychotic Prescribing Guidance and Distressed Behaviour in People Living with Dementia Toolkit

Produced by the East of England Regional Mental Health Team

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Acknowledgement to:

Cambridgeshire and Peterborough Clinical Commissioning Group (CCG); Surrey and Borders Partnership Foundation Trust; East Surrey CCG; Guildford & Waverley CCG; North West Surrey CCG, Surrey Downs CCG, Surrey Heath CCG, Greater Manchester Medicines Management Group

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Contents

Introduction

Distressed behaviour in people living with dementia can include a range of non-cognitive symptoms, such as apathy, anxiety, depression, agitation, aggression, delusions and hallucinations, walking with purpose, incontinence, altered eating habits, sexual disinhibition, shouting, hoarding, repeated questioning and sleep disturbances.

Antipsychotics are sometimes prescribed to manage distressed behaviour, however, clinical evidence shows limited benefits and this practice can threaten patient safety. It is associated with an increased risk of stroke, as well as other serious adverse events such as sedation, movement disorders such as tremors, dehydration, falls, chest infections, accelerated cognitive decline and death.

There are an estimated 1800 excess deaths and 1620 cerebrovascular accidents each year as a result of the prescription of antipsychotics to people living with dementia.

Based on this evidence, National Institute for Clinical Excellence (NICE) guidance has made clear that **antipsychotics should be only used in the first instance as a last resort in severe cases or where there is the risk of harm to the patient or others**. It is important for clinicians to try and identify a cause for the distressed behaviours and manage these, along-side carers, using non-pharmacological measures rather than resorting to drugs to treat the symptoms.

If prescribed, regular reviews of antipsychotics should be carried out with a view to reduce or discontinue prescriptions whenever possible. GPs often take on prescribing of antipsychotics which have been initiated by specialists during a secondary care admission e.g. in a general hospital. This can be challenging for GPs to manage, as there is often limited background information as to the indication for prescribing or monitoring arrangements. It should be noted, however, that it is usually straightforward for GPs to carry out discontinuation or reduction of antipsychotics.

Non-pharmacological approaches to managing distressed behaviour in people living with Dementia

It is recommended that non-pharmacological approaches are used as a first line approach (Alzheimer's Society, 2011). If a person is severely distressed or there is an immediate risk of harm to the person or others it may be necessary to offer pharmacological intervention (NICE, 2018).

What do we mean by 'distressed behaviour'? 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.

Typical causes for distressed behaviours are given in the left-hand column in the following table. The right-hand column offers suggestions in how to respond to these behaviours. These suggestions are recommended for staff with basic dementia awareness.

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

<table>
<tr><th colspan="2">Possible cause: physical health</th></tr>
<tr><th>Distressed behaviour may result from:</th><th>Ideas for carers:</th></tr>
<tr><td>Pain

Resulting from numerous causes e.g. joint, dental problems discomfort from skin problems, constipation.

People with dementia are often not able to identify or may deny pain due to their cognitive impairment / communication difficulties. Pain is hugely undiagnosed.</td><td>Use the Abbey Pain Scale to assess (Appendix 2)

Observe pain response during personal care tasks and transfers

See Pain section of this toolkit, page 9</td></tr>
<tr><td>Delirium

People with dementia have higher risk of delirium

The change in the person usually happens quickly over 1 or 2 days

Delirium can be ‘hypoactive’ (lethargy, withdrawn, not talking or eating as much), ‘hyperactive’ (agitation, hallucinations, inappropriate behaviour) or a mixture of both.
The cause is usually an underlying physical health issue which can be treated.

Delirium requires swift medical diagnosis and treatment.

The mnemonic PINCH ME is used to assess for potential causes of delirium:
 
</td><td>Ask yourself ‘is this ‘normal’ for this person?’

If ‘no’, contact a health professional to carry out an assessment for delirium

To support someone with delirium-
• Keep calm and speak in short, easy to understand sentences
• Remind them where they are and why they are there
• Reassure, don’t argue or disagree
• Remind them of the date and time and make sure they can see a clock and calendar if possible
• Make sure they have their usual glasses and hearing aids and use them
• Encourage them to eat and drink - bring food and drinks if this helps
• Ensure they have some familiar photos or objects around them
• Limit the number of visitors and reduce noise as much as possible - stimulating the resident too much can make things worse.</td></tr>
</table>

Infections UTI, thrush, chest, skin infections, cellulitis.	
Hunger, thirst and dehydration	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 May be symptom of dementias (Alzheimer's, Lewy Body and Parkinson's-related dementia) Medication side effect	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, bed sores	Are staff ensuring they are clear, loud enough, not too loud and talking into the good ear or speaking slowly enough or approaching from the side where eyesight is best?

Possible cause: medication side effects	
Distressed behaviour may result from:	**Ideas for carers:**
Medication side effects Older people with dementia may have several health conditions that require a range of medications. Multiple drug taking (polypharmacy) increases the risk of adverse effects. Medications that may cause psychotic symptoms in older people during use, or on withdrawal, include: Benzodiazepines, Anti-Parkinson drugs - levodopa, procyclidine, Anti-arrhythmics - digoxin, propranolol, Anti-inflammatories - aspirin, indomethacin, Anticonvulsants - carbamazepine, phenytoin, Steroids – prednisolone	Medication should be reviewed regularly by a pharmacist or GP to keep drug use to a minimum. A 'structured medication review' should non-medical interventions that could be used to reduce the need for medication. In a care home setting, ask for support from the multiple disciplinary team (MDT) supporting the home.

Possible cause: environmental factors	
Distressed behaviour may result from:	**Ideas for carers**
Under stimulation	Use activities that are personally relevant to interests or previous work Encourage outdoor activity such as caring for plants Provide 30 second plus spontaneous opportunities for conversations Social areas to encourage interactions Consider the use of music – playing music that brings back memories, group singing or instruments Use of electronic 'pets' or 'magic tables'
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, the garden, sitting with calming music
Specific triggers or circumstances affecting the person	Ensure you have information about the resident and their life through their personalised care and support plan, 'this is me' form and life story work so that you can get a better understanding of their behaviour. Ensure that all members of staff are aware of any residents' triggers so that they can be prevented. Identify, observe and document triggers and use consistent approach to prevent behaviour Does challenging behaviour happen after relatives have visited?
Getting used to new home 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 awareness of person's beliefs and life-style preferences	
Distressed behaviour may result from:	**Ideas for Carers:**
Lack of knowledge about the person and their beliefs and preferences	Consider using life story templates e.g. 'This is Me' (Available from the Alzheimer's Society) document 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: lack of understanding of how the person sees and interprets their world	
Distressed behaviour may result from:	**Ideas for Carers:**
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 such as pictures to indicate 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 Can be 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

Clinicians will need to be aware of and address the above factors before doing anything else; this should include taking a history of the problem, having the behaviour described by the carer/team and discussing current and past behaviour with the carer/team

The **PAIN approach** should be applied. Manage or treat any contributory factors. If the patient is not eating or drinking adequately initiate a food and fluid chart, and check that they are not over-sedated, or have dental problems e.g. ill-fitting dentures, candida infection. Pain is one of the most common causes of BPSD

Physical problems e.g. infection, pain

Activity related e.g. dressing, washing

Iatrogenic e.g. side effects of drugs such as anti-cholinergic

Noise and other environmental factors e.g. lighting, lack of stimulation

Involve the person/carers/staff in developing an ongoing person-centred care plan to address individual needs.

Identify factors that improve distressed behaviours e.g. music, dance, aromatherapy, cognitive stimulation, massage, multisensory stimulation, exercise, creative therapies, animal assisted therapies. Consider available options and tailor activities to individual preferences, skills and abilities.

Decide and record what symptom/behaviour you are treating, set up a system for monitoring it (e.g. using simple charts completed by nursing staff or carer), and monitor and record side effects closely (sedation, stiffness, tremor, mobility problems).

For mild to moderate distressed behaviours, watchful waiting or non-pharmacological interventions should be tried first. Antipsychotic treatment should only be considered if the above options have not reduced symptoms to a manageable level.

Pain

People with dementia can still experience pain and discomfort, although they might find it difficult to communicate, particularly as the disease advances. This can lead them to them exhibiting agitated, frustrated, confused, anxious, aggressive or fearful behaviour.

It can be hard to know exactly what's going on, particularly when somebody has advanced dementia and finds it very hard to communicate clearly but there may be clues in how they are behaving.

- What does their face look like? Are they grimacing or grinding or clenching their teeth?
- Are they rubbing, pointing or pulling at a particular part of their body?
- Are they irritable, crying or tearful? Are they groaning, shouting or screaming?
- What is their body language like? Are they stiff, or rocking or perhaps guarding part of their body?
- What happens when they move? Are they less mobile, or moving differently? Are they pacing, unable to settle for long, restless or fidgeting?
- Are they looking fearful? Do they seem to be seeing things or to be frightened?
- Has their appetite changed?
- Has their breathing pattern changed?

Check to see if the person has a temperature. There may be other physical clues: for example, have they recently fallen, do they have an infection or are they constipated?

Things that may be causing pain or distress:

- Sore mouth, toothache or ill-fitting dentures
- Earache
- Being lifted or moved in an uncomfortable or painful way
- Difficulty in going to the toilet or a urinary tract infection
- Painful joints
- Painful sores
- Uncut finger or toenails
- Being in an uncomfortable position or the same position for a long time

Action that might help, depending on the severity of the pain, include the following.

- Changing their position
- Touch, massage, presence and reassurance
- Cool compress, or warmth
- Using easily available painkillers such as paracetamol

Sometimes this may not be enough, and it may be necessary to speak to a doctor or a dentist, or to ask for prescription painkillers and use them if you already have been given them.

This progression from weaker to stronger types of pain relief is sometime called the "analgesic ladder".

You may need to act as an advocate or supporter for the person with dementia to make sure other pain medications are considered or tried.

Remember that pain assessment tools are available which can help you assess the person's pain and manage their symptoms (see the Abbey Pain Scale - Appendix 2).

It is important to assess pain both when the person is at rest and during activity, such as doing everyday tasks.

Considerations for New Prescriptions of antipsychotics in people with dementia

There is limited evidence for the pharmacological management of distressed behaviours in people living with dementia.

There is a high rate of spontaneous remission (or placebo effect) in trials, so watchful waiting may be useful in the case of less severe problems since up to half of all cases may be self-limiting.

For most people with dementia, the risk of harm of antipsychotic treatment outweighs the likelihood of benefit, therefore they should not be considered as first-line treatment options except in circumstances of extreme risk and harm.

Antipsychotics should be used with caution, particularly, in Parkinson's disease and dementia with Lewy bodies. There is a high risk of movement disorders (such as involuntary or uncontrollable movements, tremors and muscle contractions).

Choice of which anti-psychotic to prescribe

When the decision is made that the benefit of antipsychotic treatment outweighs the risk of harm, there are several drugs available.

The only antipsychotic currently licensed for use in all dementia is Risperidone.

Haloperidol is licensed but *only* for delirium, Alzheimer's Disease and vascular dementia. Haloperidol should be avoided if the diagnosis sub-type is unclear as there can be adverse issues in connection with Lewy Body Dementia.

Several other antipsychotics are available which can be prescribed off-license and are considered less risky.

Antipsychotic	Suitable use	Considerations
Risperidone	Licensed for all dementia sub-types	Use caution in use in people with risk factors for stroke, particularly in those with non-Alzheimer's type dementia. Use with caution in those with hepatic and renal impairment. Risk of venous thromboembolism
Haloperidol	Licensed *only* for delirium, Alzheimer's Disease and vascular dementia	Avoid if the diagnosis sub-type is unclear - adverse issues in connection with Lewy Body Dementia Risk of stroke Risk of venous thromboembolism
Quetiapine	Un-licensed Not recommended by the manufacturer for psychosis in dementia	Considered lower cardiac risk Risk of stroke Risk of venous thromboembolism
Aripiprazole	Un-licensed Not recommended by the manufacturer for psychosis in dementia	Risk of stroke Risk of venous thromboembolism
Olanzapine	Un-licensed Not recommended by the manufacturer for psychosis in dementia	Risk of stroke Risk of venous thromboembolism

Risperidone

Low dose risperidone, up to 2mg per day, is *licensed* for the treatment of behavioural disorders in dementia/older people (although that does not mean it is any safer than any other antipsychotic). **It is licensed for 6 weeks use and should be prescribed for no more than 12 weeks.**

A starting dose of 250 micrograms twice daily is recommended. This dosage can be individually adjusted by increments of 250 micrograms twice daily, not more frequently than every other day, if needed. The optimum dose is 500 micrograms twice daily for most patients. Some patients, however, may benefit from doses up to 1 mg twice daily.

Renal or hepatic impairment - The starting and consecutive dosing should be halved, and dose titration should be slower for patients with renal impairment. A once daily dose of 250 micrograms is suggested. Risperidone should be used with caution in people with hepatic impairment.

Information sources - The manufacturer's information leaflet is available via www.medicines.org.uk. Additional information for people taking risperidone is available via the Choice and medication website. A link to this website can be found here, offering information in different formats and languages.

Formulations of risperidone other than standard tablets - Risperidone is available in tablets of 500 micrograms and 1 mg. A liquid preparation (1mg/mL) should be prescribed for doses which cannot be given using the tablets. Or dispersible tablets (1 mg and 500 microgram) are available but are significantly more expensive than the liquid formulation. The smallest dose that can be measured using the pipette provided with the liquid formulation is 250 micrograms.

Prior to initiation discuss risks and benefits with the patient/relative/carer, the indication for the prescription, alternatives considered and plans for review, reduction and cessation. If use is unlicensed then consent should be obtained. All discussions about risks and benefits of use must be clearly documented

Monitoring of treatment (where possible - consider feasibility of monitoring and co-morbidities)

- Baseline –U&Es, FBC, LFTs, Prolactin, HbA1c, ECG, pulse, BP, weight, and BMI
- During dose titration – BP, pulse, extrapyramidal side effects
- 6 months, and then annually thereafter (under care of specialist) - U&Es, FBC, LFTs, Prolactin, lipids (fasting), HbA1c, Side effects, ECG, pulse, BP, weight, and BMI.

Risk of Stroke – There is an increased risk of stroke in people with dementia taking atypical antipsychotics. Risperidone should be used with caution in patients with risk factors for stroke. The risk is higher in people with non-Alzheimer's type dementia, and risperidone should not be used in this population.

Risk of venous thromboembolism (VTE) - Cases of VTE have been reported with antipsychotic drugs. All possible risk factors for VTE should be identified before and during treatment with risperidone and preventative measures undertaken.

Prescriptions for antipsychotics should be time limited and reviewed against target symptoms and side effects. Once initiated continuation should be reviewed within 6 weeks (best practice may be earlier to encourage de-prescribing) and reduction or cessation actively considered at each review. Document the therapeutic response and signs of possible adverse events including mobility, falls, sedation, low blood pressure, chest infection, and anticholinergic side-effects. Don't continue the drug if it is ineffective after a week's trial.

Patients requiring anti-psychotic medication on a regular basis for more than a week to manage behavioural disorder should in general be assessed by a psychiatric team. When prescribing, health professionals should avoid using PRN* as it can be confusing for care staff regarding when and how to administer the medication.

Consider reducing or stopping medication if appropriate after 3 months, at the latest.

If the original reason for prescribing the antipsychotics returns, then go through the above points. If initiated in secondary care, then specialists should give clear instructions of when to review and stop medication.

Be alert for and treat any coexisting emotional disorders (e.g. depression and/or anxiety and sleep disturbances). Remember that depression and anxiety are common in dementia and it is often safer to use an antidepressant as a first line treatment before considering antipsychotic medication.

Reviewing patients already prescribed an antipsychotic

When using antipsychotics use the lowest effective dose for the shortest possible time. NICE guidance advises to reassess the person at least every 6 weeks, to check whether they still need medication. An attempt should be made to withdraw treatment after 6 weeks – if this is unsuccessful and ongoing treatment is required refer for specialist advice.

Stop treatment with antipsychotics if the person is not getting a clear ongoing benefit from taking them and after discussion with the person taking them if possible, and their family members or carers.

As there are already people with dementia on antipsychotics in primary care, GPs have a key role to play in reviewing these patients with a view to stopping treatment if appropriate. This is a priority group to be offered a **structured medication review** with the focus being on reducing any inappropriate prescribing. A Structured Medication Review is a NICE approved clinical intervention designed to holistically review a person's medicines, undertaken by experts including clinical pharmacists, doctors or nurses with the resident (and family where appropriate) in the context of their clinical condition.

*PRN stands for 'pro re nata,' which means that the administration of medication is not scheduled. Instead, the prescription is taken as needed

The NHS Long Term Plan contained a commitment as part of the Ageing Well Programme to roll out the Enhanced Health in Care Homes (EHCH) model of care across England by 2024, commencing in 2020. Requirements for the delivery of EHCH by Primary Care Networks (PCNs) are included in the Network Contract Directed Enhanced Service DES for 2020/21. This includes pharmacy supported provision of Structured Medication Reviews (SMRs) and Medicines Optimisation within multidisciplinary teams (MDTs) for care homes. PCNs are contractually obliged to undertake SMRs for residents in care homes.

If it is not already available, local health systems should consider if their data systems could provide Primary Care staff with data on patients being prescribed anti-psychotics, to enable them to manage and undertake medication reviews. There may be some patients with undiagnosed dementia prescribed antipsychotics that need reviewing. It is highly recommended that there is an annual audit of patients on an antipsychotic to discover those that do not have a linked diagnosis requiring this medication.

Where antipsychotics are already prescribed for distressed behaviours in people living with dementia, all healthcare professionals should question the need for long-term use. There are emerging roles in Primary Care Networks, such as Mental Health Pharmacists, which could be developed to support medication reviews.

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) or memantine to delay cognitive decline.
- There is a detailed care plan in place for ongoing antipsychotic use.

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. The person's care plan should indicate who is responsible for reviewing, reducing and stopping the prescription to avoid any confusion.

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

It is recommended that when reviewing a number of patients in a care home, that 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.

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

The risk of recurrence of distressed behaviour after discontinuation is more likely if:

- Previous discontinuation has caused behaviour to return
- The person currently has severe symptoms

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

Antipsychotic	Usual dose range in dementia	Suggested regimen for reduction/discontinuation (generally reduce over 2–4 weeks, ideally over 4 weeks if possible)
Risperidone	250 micrograms –2 mg/day	Reduce by 250–500 micrograms every 1–2 weeks (depending on dose) then stop
Where other antipsychotics have been prescribed, the advice below may assist when stopping treatment. Confirm indication and rationale for stopping with specialist.		
Amisulpride	25–50 mg/day	Reduce by 12.5–25 mg every 1–2 weeks (depending on dose) then stop
Aripiprazole	5–15 mg/day	Reduce by 5 mg every 1–2 weeks (depending on dose) then stop (if patient is on 5 mg daily, reduce to 2.5 mg for 2 weeks. Note that tablets are not scored and liquid is expensive – contact local pharmacist for advice)
Haloperidol	Not recommended in older people with dementia (except in delirium). Reduce by 250–500 micrograms every 1–2 weeks (depending on dose) then stop	
Olanzapine	2.5–10 mg/day	Reduce by 2.5 mg every 1–2 weeks (depending on dose) then stop
Quetiapine	12.5–300 mg/day	For doses 12.5–100 mg/day, reduce by 12.5–25 mg every 1–2 weeks (depending on dose) then stop For doses >100–300 mg/day, reduce by 25–50 mg every 1–2 weeks (depending on dose) then stop If dose is 300 mg/day, reduce to 150–200 mg/day for 1 week then by 50mg per week

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.

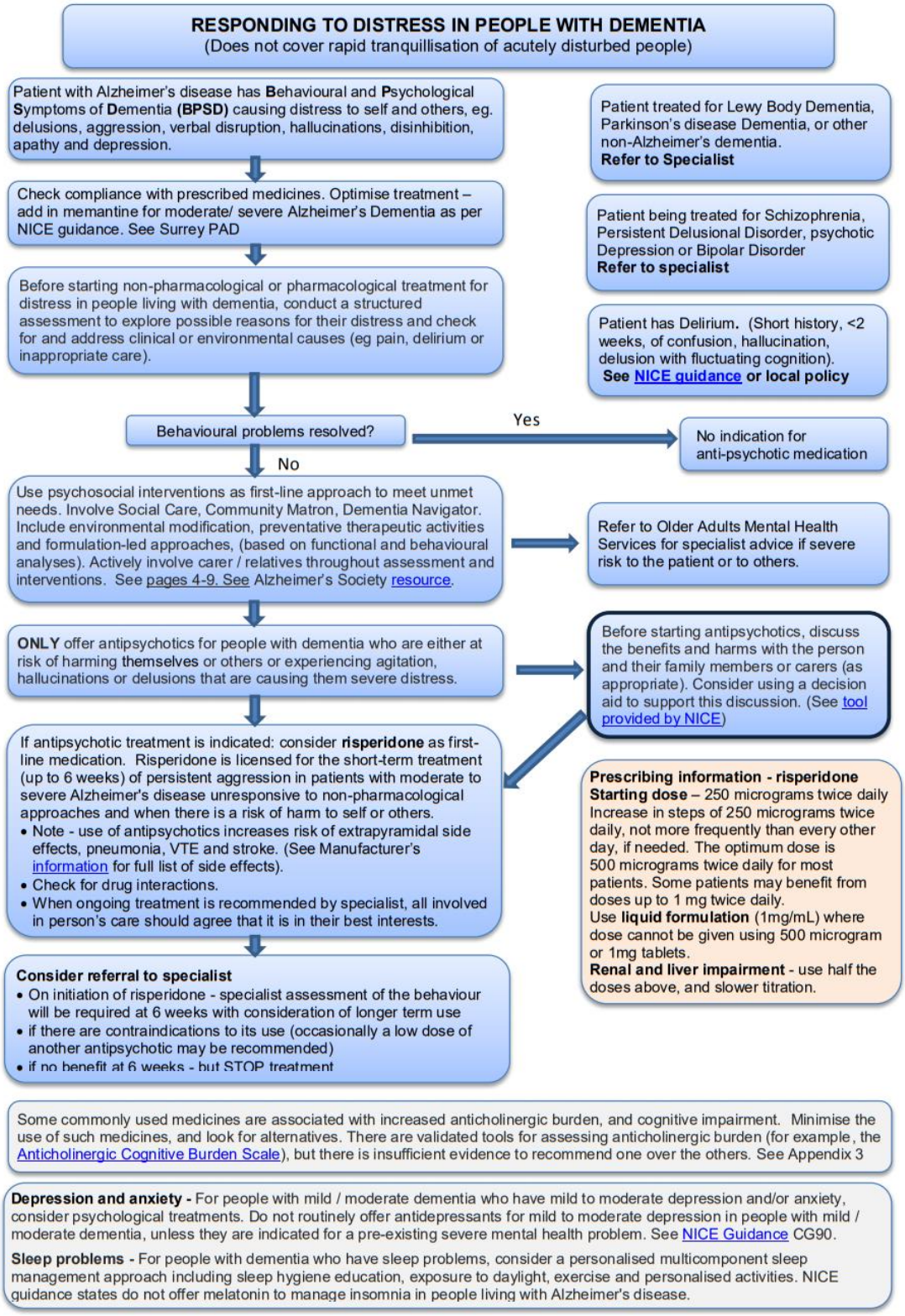
In some cases, it may be necessary to withdraw the drug more slowly, particularly if symptoms reappear.

- Implement small decreases in dose (ensure dose reduction is possible with strengths available), one step down at a time.
- Where the anti-psychotic is given more than once daily, decrease only one dose to start with, choosing the dose where patient is likely to be least affected.
- Allow enough 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 daily then administer on alternate days before stopping completely.

If any medication is stopped, make sure the repeat prescribing record is updated including the rationale for stopping treatment, to prevent a further supply being prescribed.

If the patient is difficult to manage or distressed behaviour returns, seek advice from local mental health trusts.

Summary flowchart – responding to distressed behaviours



Glossary of key terms

Anticholinergics (ACh) are a group of substances used to treat the side-effects of antipsychotic medication by blocking the action of the neurotransmitter acetylcholine to treat extrapyramidal symptoms. These medications are also associated with side-effects including blurred vision, dry eyes, urinary retention, heat intolerance, cognitive impairment, delirium and delusion.

Anticholinergic burden (ACB) is the cumulative effect of taking multiple medications which have anticholinergic properties. This measure is used to recognise which adverse symptoms may be caused by medication or a combination or medications, or by cognitive decline and physiological changes associated with ageing and dementia.

Atypical antipsychotics, sometimes known as second generation antipsychotics (SGAs), are a type of antipsychotic drug introduced in the 1990s for the treatment of psychiatric conditions. Virtually all the antipsychotics prescribed for dementia are **atypical** as the generation of typical antipsychotics developed in the 1950s have fallen out of favour.

Cholinesterase inhibitor is a class of drug which prevent the normal breakdown of acetylcholine, the primary neurotransmitter found in the body which has functions in the peripheral and central nervous system. These drugs are used as a treatment for dementia and include Donepezil, Galantamine and Rivastigmine.

Disinhibition is a lack of restraint and the inability to withhold or suppress inappropriate, dangerous or impulsive behaviour. This is a common behavioural and psychological symptom of dementia.

Extrapyramidal symptoms or side-effects are drug-induced impairments in the body which can include dystonia (muscle spasms and contractions), akathisia (motor restlessness), slowness of movement, rigidity and tremor. These symptoms are common side-effects of the use of anti-psychotics and are often treated using anticholinergic medication.

FBC or full blood count is a full blood examination, a set of tests which provide information about the counts of different kinds of cells in the blood (white blood cells, red blood cells, platelets, the concentration of haemoglobin, and the haematocrit or volume percentage of red blood cells). The FBC is used as part of baseline monitoring of treatment.

HbA1c is a measure of how well-controlled blood sugar has been over a period of 3 months. It provides a good idea of how high, low or average blood glucose levels have been and is therefore an important monitoring test.

Hepatic impairment is an impairment to or the decline of the liver. This can alter the response to drugs in several ways, including impaired metabolism. Antipsychotic medications such as risperidone should only be used with caution in someone with hepatic impairment.

Lewy Bodies are clumps of protein in the brain which can build-up and affect chemicals in the brain, which in turn can lead to issues with memory, movement, thinking skills and behaviour.

Lewy Body Dementia (LBD) is a type of dementia caused by abnormal deposits of Lewy bodies in the brain. It is a common variety of dementia and is associated with a decline in thinking, reasoning, mood and independent function.

LFT or liver function tests are a specific range of blood tests which provide information about the state of the liver.

Lipids are fatty acids or derivatives which are found in the blood (cholesterol and triglycerides) and which can be measured as part of routine health tests as a determinant of high cholesterol.

Neuroleptic is another term for an antipsychotic medication and refers to the suppression of nerve functions.

Iatrogenic is the causation of a disease or symptom by treatment or diagnosis. For example, the side-effects of anti-psychotic drugs when used to treat patients with dementia.

Placebo is a substance or treatment which is designed to have no therapeutic value. In some medical trials, a placebo is used as a control measure to prevent the recipient knowing whether they are receiving a real treatment. This is because expectations and beliefs about medical treatment can impact how effective they are.

Plasma glucose is the volume of blood in blood glucose, which is the specific component of blood which holds the blood cells of whole blood in suspension.

PRN stands for 'pro re nata' which means that the administration of medication is not scheduled. Instead, the prescription is taken as needed

Prolactin is a protein used in the production of milk and secreted by the pituitary gland. It plays an essential role in metabolism and the immune system and its monitoring is an important component of baseline health monitoring.

Renal impairment is impairment to or the decline of the kidney. Decline in kidney function is common in old age and makes the organ less effective at secreting a drug which might be toxic or otherwise cause illness. For this reason, the dosage of antipsychotics should be lowered if the patient has renal impairment.

Spontaneous remission is an unexpected improvement or cure from a progressive disease. In a drug trial, a placebo (see above) is used to account for the possibility of the condition of a disease improving without a known cause. When trialling a drug, it is important to be watchful as the high rate of spontaneous remission in trials of antipsychotics indicates the patient may not be improving because of the drug.

U&Es is an abbreviation for urea and electrolytes, which provide useful information about the volume of blood and its PH and specifically kidney functioning.

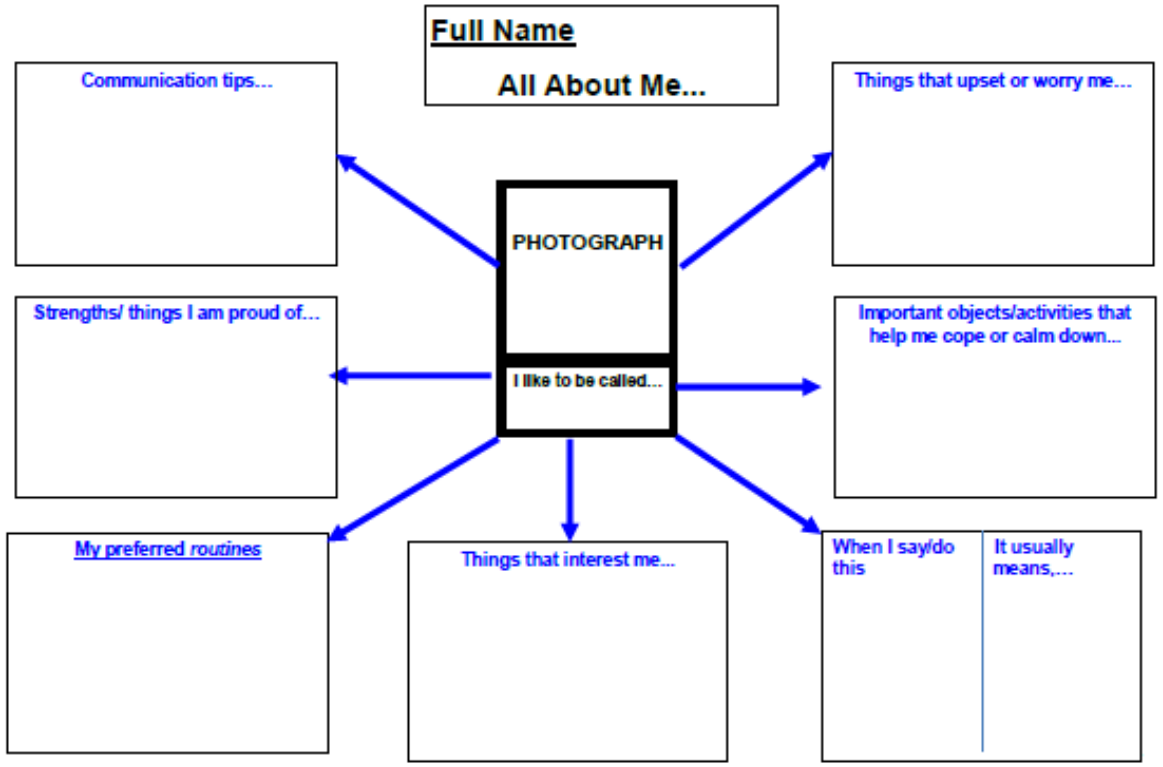
Vascular dementia is a common type of dementia caused by reduced blood-flow to the brain. It affects around 150,000 people in the UK.

Thromboembolism or deep vein thrombosis is a condition where blood clots form in veins deep inside the body. This can cause stroke, pulmonary embolism and other health issues and is a significant cause of morbidity and death in adults. Treatment typically involves anticoagulants (blood thinners), aspirin or vasodilators which relax and widen vessels.

Appendices

Appendix 1: 'All About Me'

This document can be used to help health and social care staff to better understand the person with dementia so care can be more personalised. This can help to reduce distressed behaviours.



Appendix 2: The Abbey Pain Scale

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalize.

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

Name of resident: .....

Name and designation of person completing the scale: .....

Date: .....**Time:** .....

Latest pain relief given was.....at .....hrs.

Q1. **Vocalization**
eg. whimpering, groaning, crying **Q1** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q2. **Facial expression**
eg: looking tense, frowning grimacing, looking frightened **Q2** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q3. **Change in body language**
eg: fidgeting, rocking, guarding part of body, withdrawn **Q3** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q4. **Behavioural change**
eg: increased confusion, refusing to eat, alteration in usual patterns **Q4** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q5. **Physiological change**
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor **Q5** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q6. **Physical changes**
eg: skin tears, pressure areas, arthritis, contractures, previous injuries. **Q6** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for 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 which matches the type of pain ⇨

Chronic	Acute	Acute on Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

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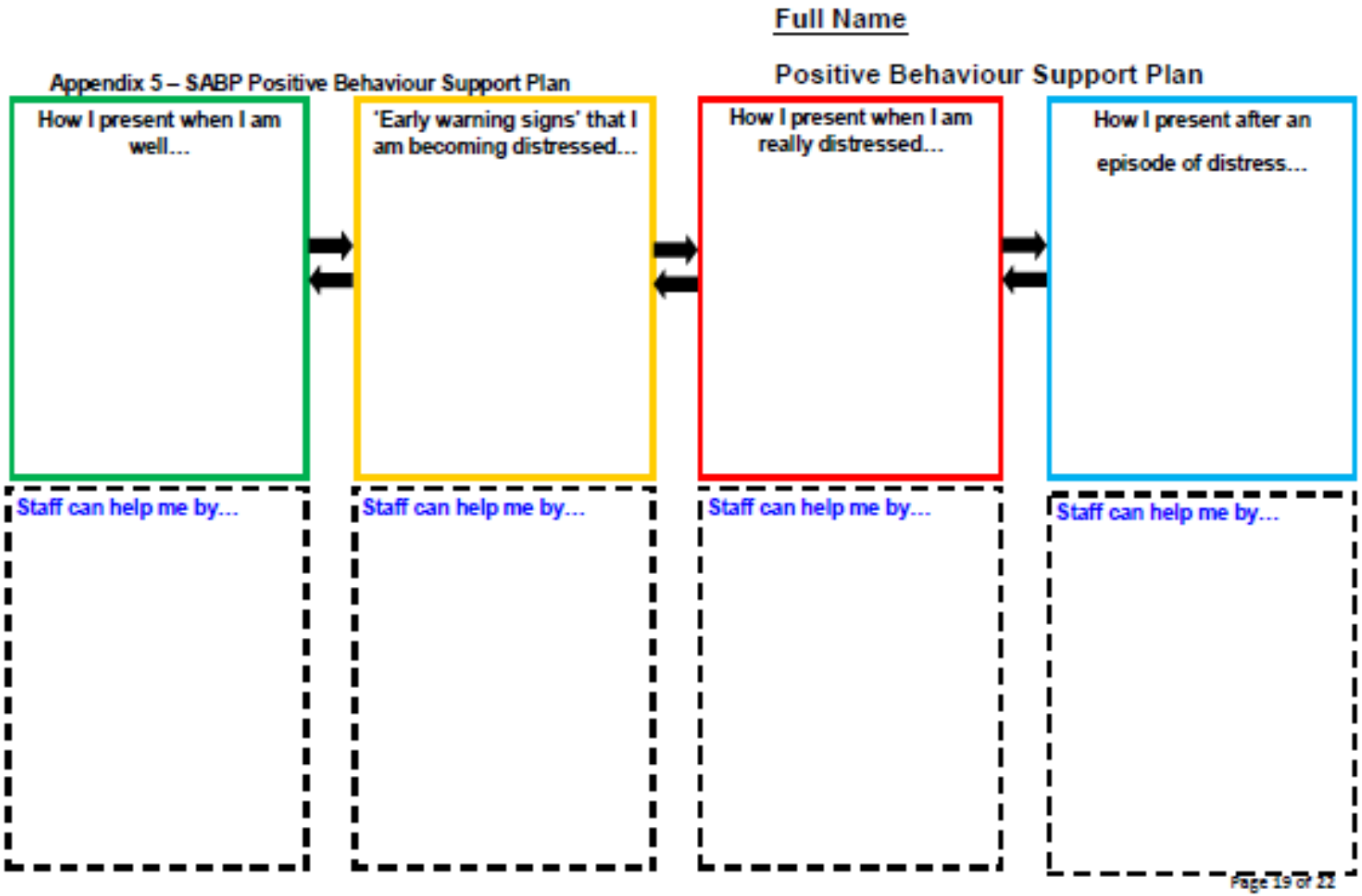
Appendix 3: Behaviour Support Plan



Appendix 4: Carer completed distress behaviour symptom recording form for people living with dementia (COMPLETED EXAMPLE)

1. Describe the unwanted behaviour(s) that concern you as a carer in the first column.

2. At the end of each day, put the appropriate code in the column and make a comment if you wish.

3. Ideally the same person should complete the form each day.

4. 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												
Symptoms	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
Hitting out when trying to wash and dress him.	*A*	*B*	*A*	*A*	*B*	*B*	*A*	*B*	*B*	*A*	*A*	*A*	*B*
Shouting loudly and unexpectedly for no apparent reason.	*A*	*A*	*A*	*A*	*B*	*A*	*A*	*A*	*B*	*B*	*A*	*A*	*B*

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.*
25.02	*Medicines were adjusted by GP*
26.02	*Really calm today and more alert but calm.*
28.02	*A bad day today but manageable.*

Appendix 5: Carer completed distress behaviour symptom recording form for people living with dementia (BLANK EXAMPLE)

Carer completed non-cognitive symptom recording form for people living with dementia

Name …….

1. Describe the unwanted behaviour(s) that concern you as a carer in the first column.

2. At the end of each day, put the appropriate code in the column and make a comment if you wish.

3. Ideally the same person should complete the form each day.

4. 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												
Symptoms													

Date	Comment

Appendix 6: Assessment of patient with non-cognitive symptoms

Table 1: Assessment of patient with non-cognitive symptoms.

Assess patient early to identify factors that may influence behaviour. Include:-

Physical Health	Suitable physical examination Any acute medical problems i.e. delirium Exclude infection (especially UTI) Exclude possible undetected pain or discomfort Is patient dehydrated? Any chronic disease that may have become unstable or relapsed?
Mental Health	Assess for anxiety and depression
Side-effects of medication	What medication is the patient on? Assess for side-effects of medication (including acetylcholinesterase inhibitors). Has any new medication recently been started?
Psychosocial factors	Individual biography Religious beliefs, spiritual and cultural identity Against who is the aggression directed? Is there a reason? Physical environmental factors. Is the patient bored? Behavioural and functional analysis in conjunction with carers and care workers

Appendix 7: Anticholinergic Burden

Background

Anticholinergics should be prescribed with caution as elderly patients are more likely to experience adverse effects such as constipation, urinary retention, dry mouth/eyes, sedation, confusion, delirium, photophobia, falls and reduced cognition (may lead to wrong diagnosis of dementia). Systematic reviews and meta-analysis show that there appears to be some association between anticholinergic drugs and cognitive impairment, falls and mortality.

The Anticholinergic Burden (ACB) score is useful to raise awareness of the anticholinergic effects of different medicines. A number of studies have been published which aim to assign drugs with one, two or three points; the higher the number, the stronger the anticholinergic effect.

Recommended Action

- Identify older or frail people or people with complex multi-morbidities taking anticholinergic drugs.
- Minimise the use of anticholinergic drugs where possible. If an older adult is prescribed an anticholinergic medication which has been assigned a score of 2 or 3, or if they are on a range of drugs that add up to an ACB score of 3 or more, then an informed decision should be made to either discontinue medication if there is no absolute need, or to switch to medication with a lower ACB score or from a different class.
- Review at regular intervals for efficacy or tolerance.
- Review medication in older people that have had a fall or are at increased risk of falling as part of a multifactorial risk assessment.

In patients with dementia:

• Perform a medication review to identify and minimize use of drugs that may adversely affect cognitive function.

• Avoid prescribing anticholinergics with acetylcholinesterase inhibitors.

• If there is a suspicion of anticholinergic induced impaired cognition, carry out a mini mental state examination (or equivalent) and consider switching or stopping if confirmed and clinically appropriate.

(adapted from PresQIPP B140. Anticholinergic Drugs)

Appendix 8: Drugs on the Anticholinergic Cognitive Burden Scale

Drugs on the Anticholinergic Cognitive Burden (ACB) scale

Aging Brain Care. Anticholinergic Cognitive Burden Scale. 2012 update. Available on the *University of East Anglia Website:* www.uea.ac.uk/documents/3306616/10940915/Anticholinergics/088bb9e6-3ee2-4b75-b8ce-b2d59dc538c2

ACB score 1 (mild)	ACB score 2 (moderate)	ACB score 3 (severe)
Alimemazine	Amantadine	Amitriptyline
Alprazolam	Belladona alkaloids	Amoxapine
Alverine	Carbamazepine	Atropine
Atenolol	Cyclobenzprine	Benztropine
Beclometasone dipropionate	Cyproheptadine	Chlorpheniramine
Bupropion	Loxapine	Chlorpromazine
Captopril	Meperidine	Clemastine
Cimetidine	Methotrimeprazine	Clomipramine
Clorazepate	Oxcarbazepine	Clozapine
Codeine	Pethidine	Darifenacin
Colchicine	Pimozide	Desipramine
Dextropropoxyphene		Dicyclomine
Diazepam		Diphenhydramine
Digoxin		Doxepin
Dipyridamole		Flavoxate
Disopyramide phosphate		Hydroxyzine
Fentanyl		Imipramine
Fluvoxamine		Meclozine
Furosemide		Nortriptyline
Haloperidol		Orphenadrine
Hydralazine		Oxybutynin
Hydrocortisone		Paroxetine
Isosorbide		Perphenazine
Loperamide		Procyclidine
Metoprolol		Promazine
Morphine		Promethazine
Nifedipine		Propantheline
Prednisone		Mepyramine
Prednisolone		Solifenacin
Quinine		Scopolamine
Ranitidine		Tolterodine
Theophylline		Trifluoperazine
Timolol		Trihexyphenidyl
Trazodone		Trimipramine
Triamterene		Trospium
Warfarin		

Appendix 9: Baseline measurements before initiating Risperidone

Table 2: Baseline measurements before initiating Risperidone

Risperidone is the only antipsychotic licensed for the short-term treatment (up to 6 weeks) of persistent aggression in patients with moderate to severe Alzheimer's dementia unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others.

NB- If baseline measurements are not carried out before initiating risperidone and a side-effect develops it will be difficult to decide whether the effect was due to risperidone or if it was already there.

	Baseline	After initiation of risperidone
Body weight	✓	at 3 months then yearly
Serum U&E's	✓	Yearly
FBC	✓	Yearly
Plasma glucose	✓	at 4 – 6 months then yearly
Blood pressure and pulse	✓	monitor frequently during dose titration
ECG	✓	Where possible, then monitor after dose changes and if there is evidence of other risk factors such as relevant personal/family history, co-prescription of drugs that prolong QT interval or lower potassium
Prolactin	✓	at 6 months then yearly
LFTs	✓	Yearly
Creatinine Phosphokinase	✓	measure again only if Neuroleptic Malignant Syndrome suspected

Appendix 10: Review checklist – antipsychotics in dementia

Antipsychotics in Dementia – Review Checklist

Adapted from NHS South West Partnership

Patient name	
Date of birth	
Antipsychotic prescribed and dose	

Background information:

Have cerebrovascular risk factors been assessed?	**YES / NO**
Has there been a baseline assessment of cognitive function?	**YES / NO**
Have the target symptoms (that the medication should be improving) **been identified, quantified and documented? e.g. Hallucinations**	**YES / NO**
Was antipsychotic treatment indicated? (*)	**YES / NO**
Were the risks / benefits of treatment discussed with the patient and / or carer & documented in the notes?	**YES / NO**
Have baseline measurements been carried out? (see table 2)	**YES / NO**
Has discontinuation been attempted previously?	**YES / NO**
Does the patient have an individual care plan?	**YES / NO**
Has a date for review of treatment been set?	**YES / NO**

* **Antipsychotics should not be used for mild to moderate non-cognitive symptoms**. Medication for non-cognitive symptoms or behaviour that challenges should only be considered as a first-line option **if there is severe distress or an immediate risk of harm to the person with dementia or others.**

Ongoing review of treatment

Date of the review	
Current antipsychotic and dose	
Have target symptoms been assessed (for therapeutic response) **and been clearly documented? e.g. Hallucinations**	**YES / NO**
Has cognitive function been assessed (for decline)**?**	**YES / NO**
Has the patient been assessed for antipsychotic side effects / adverse effects? (E.g. mobility, falls, sedation, extra pyramidal symptoms, BP and pulse, blood glucose, infection, anticholinergic S/Es, weight & central obesity. In patients with DLB monitor for severe untoward neuroleptic sensitivity reactions)	**YES / NO**
Is antipsychotic to be continued?	**YES▼ / NO**

▼ **If YES, document reason why in the notes and discuss with patient and/or carers. Set another date for review.**

Appendix 11: Further sources of advice and guidance

Alzheimer's Society Website
Contains a wide selection of fact sheets, in particular:
o Changes in Behaviour
o Challenging Behaviour in Dementia
o Staying healthy with sleep
o Sleep disturbance and waking up at night
o "This is me" document
o Drugs used to relieve behavioural and psychological symptoms
o Preventing and managing aggressive behaviour

Life Story Network, Knowing Me! Dementia Depression and Delirium – A person centred education and training resource.
Life Story Network offer tailored training for the health & social care sector into improving quality of life of people with dementia. The training package covers relationship-based, person-centred care, supporting family and friends and meaningful activity and occupation.

Choice and Medication
This website provides information leaflets on medicines, and a series of information leaflets on dementia and Alzheimer's disease.

Electronic Medicines Compendium
For prescribing information and manufacturer's patient information leaflets

Dementia UK
A charity committed to improving quality of life for all people affected by dementia.

Management of dementia in primary care
A module provided by BMJ Learning

National Council for Palliative Care.
How Would I Know What I Can Do? How to help someone with dementia who is in pain or distress

NHSE/I South East Clinical Delivery and Networks
Dementia and Older People's Mental Health: Guidance for Primary Care Networks and Care Homes

NICE Decision aid
Antipsychotic medicines for treating agitation, aggression, and distress in people living with dementia.

NICE Dementia Quality Standard QS184
Published June 2019

NICE. Dementia: assessment, management and support for people living with dementia and their carers. NICE guideline 97
Published June 2018

SCIE (Social Care Institute for Excellence)
Fact sheets, online training, training videos

Taylor D, Barnes T, Young A. Maudsley Prescribing Guidelines in Psychiatry. 13th Edition. Wiley Blackwell 2018