GP Resource Pack

Reducing Antipsychotics in People Living with Dementia

Version 6 – January 2018

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Approved by the Sussex Partnership NHS Foundation Trust’s Drugs & Therapeutics Group on 29th January 2018

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

1. All patients with dementia currently on antipsychotics or memantine for behavioural problems who have not had a trial discontinuation in the last 3 months should have the antipsychotic or memantine 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 or memantine 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. 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 or memantine are stopped first, to give the home confidence in the process.

5. Unless there is a detailed care plan indicating memantine’s use is long-term or when it should be stopped by the GP, responsibility for reviewing and stopping the memantine lies with the specialist team and the patient should be referred for a review.

6. To assist in this process GPs will be provided with a resource pack including:
   - This guidance.
   - A pain assessment tool for people with dementia.
   - A basic introduction to behavioural approaches to minimize BPSD.
   - An information sheet for carers/relatives.
   - A sample chart and blank chart for carers to use to keep a diary of behaviour, before and after stopping treatment.
   - A form to record the decision to initiate an antipsychotic.
   - A form to record that a review of re-prescribed antipsychotic has been done.
   - Two suggested audit tools.
• Guidelines for treating BPSD.
• A list of useful websites.

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

8. 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.

9. Unless the current dose is very low it is suggested the dose is halved first before considering stopping and if very high halved and halved again before stopping (if the very high dose was recommended by secondary care, get advice from them before initiating any change). 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.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Total daily dose</th>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risperidone</td>
<td>Up to 500 micrograms</td>
<td>Stop</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Up to 1mg</td>
<td>Halve dose</td>
<td>Stop</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Over 1mg</td>
<td>Halve dose</td>
<td>Halve dose</td>
<td>Stop</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>25mg</td>
<td>Stop</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Up to 50mg</td>
<td>Halve dose</td>
<td>Stop</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Over 50mg</td>
<td>Halve dose</td>
<td>Halve dose</td>
<td>Stop</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>Up to 500 micrograms</td>
<td>Stop</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Up to 1mg</td>
<td>Halve dose</td>
<td>Stop</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Over 1mg</td>
<td>Halve dose</td>
<td>Halve dose</td>
<td>Stop</td>
</tr>
</tbody>
</table>

10. 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.

11. 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.

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

13. 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. Document any non-pharmacological approaches used and whether they were successful or unsuccessful.
14. 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.

15. 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 stop date on a Monday, so benefits and risks can be reassessed at regular intervals.

16. If an antipsychotic is needed, risperidone should be used first-line, due to its short-term licence, or if not tolerated, olanzapine. Quetiapine should not routinely be used, as evidence shows it is not as effective as risperidone and has a similar side-effect profile.

17. Medical staff in the local Older Peoples Mental Health team are available by telephone to advise GPs if advice is wanted when assessing the ongoing benefits of continuing antipsychotic use. GPs should ring their local team, leaving a message if a specialist is not immediately available, including a contact number and a good time to take a returned the call.

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

Note - that 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”.

Note: A literature review was undertaken in November 2017 by the Medicines Information Department of the Western Sussex Hospitals NHS Foundation Trust on new literature published since October 2015 on the use of medication to treat BPSD and came up with the following summary:

‘In summary, guidance provided in the GP Resource Pack with regards to antipsychotic prescribing is in line with current evidence. There appears to be no new or conflicting information to that which is provided in the guidance. Increased risk of all-cause mortality due to antipsychotics, need for reduction in antipsychotics and risperidone being the only UK licensed drug for this indication is still the same as 2015 and there appears to be no new findings about this. With regards to comparison of efficacy and risks of different evidence, there does not appear to be any change to existing knowledge, with literature since 2015 supporting research established prior to this.’

A copy of the literature search is available from ray.lyon@sussexpartnership.nhs.uk

Updated October 2015 and reviewed unchanged January 2018  Review January 2020
**Pain Assessment in Advanced Dementia (PAINAD) Scale**

<table>
<thead>
<tr>
<th>Items*</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan. Low level speech with a negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch.</td>
<td>Unable to console, distract or reassure.</td>
<td></td>
</tr>
</tbody>
</table>

*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").

**Breathing**

1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional laboured breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. 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.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

**Negative vocalization**

1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.
Facial expression

1. Smiling is characterized 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.

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

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

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

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

Body language

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

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

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

4. Fidgeting is characterized 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.

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

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

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

8. Pulling or pushing away is characterized 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.

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

Consolability

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

2. Distracted or reassured by voice or touch is characterized 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.

3. Unable to console, distract or reassure is characterized 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.

Reference


Non-pharmacological Approaches to Psychological and Behavioural Distress in People with Dementia, a guide for GPs
Version 2

It is recommended that non-pharmacological approaches are used as a first line approach (Alzheimer’s Society, 2011). 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 (NICE, 2006).

What do we mean by ’psychological and behavioural distress’ or ‘behaviour that challenges’?

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 psychological and behavioural distress are given in 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 (fact sheets)

DementiaUK – helpline for professionals for advice re: individuals

SCIE website – fact sheets, online training, training videos

Links for these are available on a separate sheet. In the resource pack

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With original advice from:

Kate Budge, Assistant Psychologist
Victoria Wray, Team Leader for care Home Reach
Stephanie Giles, Team Leader for Care Home Reach

Updated by Sally Stapleton, Clinical Psychologist
Possible cause: physical health and medication side effects

<table>
<thead>
<tr>
<th>Psychological and behavioural distress may result from:</th>
<th>Ideas for staff:</th>
</tr>
</thead>
</table>
| **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 PAIN-AD to assess.  
• Observe pain response during personal care tasks and transfers |
| **Delirium**  
• People with dementia at higher risk  
• Requires medical diagnosis and treatment for underlying causes | |
| **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 | • 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? |
| **Medication side effects – GP review** | |

Possible cause: environmental factors

<table>
<thead>
<tr>
<th>Psychological and behavioural distress may result from:</th>
<th>Ideas for staff</th>
</tr>
</thead>
</table>
| **Under stimulation** | • Use activities that are personally relevant to interests or previous work  
• Provide 30 sec - 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 behavioural and psychological distress happen after relatives have visited? | Refer to specialist mental health services for functional analysis and behavioural interventions |
| Getting used to 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 awareness of person’s beliefs and life-style preferences**

<table>
<thead>
<tr>
<th>Psychological and behavioural distress may result from:</th>
<th>Ideas for Staff:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge about the person and their beliefs and preferences.</td>
<td>Consider using life story templates e.g. ‘This is Me’ document to gather information.</td>
</tr>
<tr>
<td></td>
<td>Promote respect for religious or cultural rules and customs</td>
</tr>
<tr>
<td></td>
<td>Consider whether person thinks they are younger with work or care responsibilities, e.g., need to collect children from school or go to work</td>
</tr>
<tr>
<td></td>
<td>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</td>
</tr>
<tr>
<td></td>
<td>Check attitudes towards physical touch</td>
</tr>
<tr>
<td></td>
<td>Consider beliefs about people of different age, gender, race/colour</td>
</tr>
<tr>
<td></td>
<td>Promote work with family members to inform care and better understand the resident</td>
</tr>
</tbody>
</table>

**Possible cause: lack of understanding of how the person sees and interprets their world**

<table>
<thead>
<tr>
<th>Psychological and behavioural distress may result from:</th>
<th>Ideas for Staff:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person unable to communicate their needs or requests are being ignored.</td>
<td>Be proactive with checking person’s needs at frequent intervals</td>
</tr>
<tr>
<td></td>
<td>Use short simple sentences or statements or non-verbal gestures to indicate walking to toilet, etc.</td>
</tr>
</tbody>
</table>
| 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) |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties in recognizing everyday objects</td>
<td>• Use alternative means to aid recognition, e.g. flushing toilet, holding the object, carer to demonstrate use of object</td>
</tr>
<tr>
<td>Repetitive behaviours</td>
<td>• Use distraction, reassurance, emotion-focused strategies</td>
</tr>
</tbody>
</table>
| 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 ignores 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: underlying emotional or mental health problems**

<table>
<thead>
<tr>
<th>Psychological and behavioural distress may result from:</th>
<th>Ideas for Staff:</th>
</tr>
</thead>
</table>
| Undiagnosed depression and anxiety  
• GP to use Cornell Depression Scale to assess  
Depression is commonly experienced by people with dementia and is often undiagnosed and 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 |

Updated January 2018  
Review January 2020
Carer Information leaflet

Reducing or stopping antipsychotic medication in people living with dementia

The latest evidence suggests that some medicines used to treat unwanted behaviour 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 unwanted behaviour may disappear or become less troublesome over time, even without medication.

It has been decided by the practice that most patients being prescribed an antipsychotic for unwanted behaviour should have this medicine reduced or stopped to see if it is still needed. It is our intention to try and reduce the dose of the antipsychotic in approximately one week’s time. If possible we hope to eventually stop it completely. If you have any concerns, please do not hesitate to contact the practice for advice.

Clinical trials have shown that when stopping antipsychotic 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 unwanted behaviour returning or a heightened sensitivity to any unwanted behaviour. To help properly assess whether behaviour has significantly changed after the antipsychotic is reduced or stopped we would like you to complete a diary. Please start filling it in one week before the medication is due to reduced or stopped. The diary sheet has been designed for you to record on it the types of behavioural problems you are concerned about. You can then record how troublesome they are each day.

Once the medication is reduced or stopped, please keep recording any unwanted behaviour for at least 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 keep a supply of the medicine we are reducing or stopping, just in case. Even if a medicine is restarted for unwanted behaviour, the intention is to regularly try and reduce or stop it again at some point to assess its on-going 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 unwanted behaviour returns. Please take any medicines no longer needed back to your community pharmacy or dispensing doctor for safe disposal.

October 2015 (reviewed unchanged January 2018) Review January 2020
Carer completed behavioural distress recording form for people living with dementia – COMPLETED SAMPLE

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, continuing on the back of the form if needs be.
3. Start 7 days before the medication is reduced or stopped and continue until at least 7 days after the medication is stopped.
4. Ideally the same person should complete the form each day.
5. Use an additional form if necessary.

Column codes

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

<table>
<thead>
<tr>
<th>Date medication reduced (if appropriate)</th>
<th>Date medication stopped: 23 February 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptoms</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Hitting out when trying to wash and dress him.</strong></td>
<td>16/02 A 17/02 B 18/02 A 19/02 A 20/02 B 21/02 B 22/02 A 23/02 B 24/02 A 25/02 A 26/02 A 27/02 B 28/02 A 29/02 A</td>
</tr>
<tr>
<td><strong>Shouting loudly and unexpectedly for no apparent reason.</strong></td>
<td>16/02 A 17/02 A 18/02 A 19/02 B 20/02 A 21/02 A 22/02 A 23/02 B 24/02 B 25/02 A 26/02 A 27/02 B 28/02 A 29/02 A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>17.02</td>
<td>Agitated after breakfast when washed but calmed down later.</td>
</tr>
<tr>
<td>19.02</td>
<td>Really calm today.</td>
</tr>
<tr>
<td>Date</td>
<td>Comment</td>
</tr>
<tr>
<td>-------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>20.02</td>
<td>Dad was discovered to have a temperature and once given some paracetamol he calmed down.</td>
</tr>
<tr>
<td>23.02</td>
<td>Still on regular paracetamol</td>
</tr>
<tr>
<td>24.02</td>
<td>Paracetamol stopped after lunch and temperature stayed normal. More agitated than normal though.</td>
</tr>
<tr>
<td>26.02</td>
<td>Really calm today and more alert but calm.</td>
</tr>
<tr>
<td>28.02</td>
<td>A bad day today but manageable.</td>
</tr>
</tbody>
</table>
Carer completed behavioural distress recording form for people living with dementia

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, continuing on the back of the form if needs be.
3. Start 7 days before the medication is reduced or stopped and continue until 7 days after the medication is stopped.
4. Ideally the same person should complete the form each day.
5. 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:

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Date</th>
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<table>
<thead>
<tr>
<th>Date</th>
<th>Comment</th>
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</table>
Dementia services community team details as of January 2018

If requesting advice on reducing, stopping or restarting an antipsychotic please leave a message at the team base, leaving details of your contact number and the best times to be contacted.

<table>
<thead>
<tr>
<th>Team</th>
<th>Address</th>
<th>Contact number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brighton &amp; Hove</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B &amp; H East SOAMH Team</td>
<td>EBCMHC, Brighton General Hospital, Elm Grove, Brighton, BN2 3EW</td>
<td>01273 265602</td>
</tr>
<tr>
<td>B &amp; H West SOAMH Team</td>
<td>Millview Hospital, Nevill Avenue, Hove, BN3 7HZ</td>
<td>01273 242038</td>
</tr>
<tr>
<td><strong>East Sussex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eastbourne, Hailsham &amp; Seaford SOAMH Team</td>
<td>2nd Floor, St Mary's House, 52 St Leonard's Road, Eastbourne, BN21 3UU</td>
<td>01323 747223/4</td>
</tr>
<tr>
<td>Hastings &amp; Rother SOAMH Team</td>
<td>Cavendish House, Breeds Place, Hastings, PN34 3AA</td>
<td>01424 724848</td>
</tr>
<tr>
<td>HWL&amp;H ATS - Dementia (Newhaven base)</td>
<td>Hill Rise, Newhaven Rehab Centre, Newhaven, BN9 9HH</td>
<td>01273 616440</td>
</tr>
<tr>
<td>HWL&amp;H ATS - Dementia (Uckfield base)</td>
<td>Millwood, Uckfield Community Hospital, Uckfield, TN22 5AW</td>
<td>01825 761177</td>
</tr>
<tr>
<td><strong>West Sussex</strong></td>
<td></td>
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</tr>
<tr>
<td>Western Sussex LWWD Team</td>
<td>Harold Kidd Unit, Blomfield Drive, Chichester, PO19 6AU</td>
<td>01243 791833</td>
</tr>
<tr>
<td>Memory Assessment Team</td>
<td>Harold Kidd Unit. Bloomfield Drive Chichester PO19 6AU</td>
<td>01243 791883</td>
</tr>
<tr>
<td>Later Life Team</td>
<td>Chapel Street Clinic, Chichester, PO19 1BX</td>
<td>01243 623400*</td>
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<tr>
<td>North West Sussex LWWD Team</td>
<td>New Park House, North Street, Horsham, RH12 1RJ</td>
<td>01403 223244</td>
</tr>
<tr>
<td>Mid Sussex – LWWD Team</td>
<td>Linwood CMHC, Butlers Green Road, Haywards Heath, RH16 4BE</td>
<td>01444 416606</td>
</tr>
<tr>
<td>Adur, Arun &amp; Worthing – LWWD Team</td>
<td>Chanctonbury, Swandean, Arundel Road, Worthing, BN13 3EP</td>
<td>01903 843888</td>
</tr>
</tbody>
</table>

Please note:  
SOAMH Team = Services for Older Adults Mental Health Team  
LWWD Team = Living Well with Dementia Team  
HWL&H = High Weald, Lewes and Havens  
ATS = Assessment and Treatment Service

January 2018  
Review January 2020
Audit tool for patients diagnosed with dementia on antipsychotics

<table>
<thead>
<tr>
<th>Patient identifier</th>
<th>Gender</th>
<th>Living where (note 1)</th>
<th>Dementia type (note 2)</th>
<th>Anti-psychotic Yes/No (note 3)</th>
<th>If yes, type? (note 4)</th>
<th>Other diagnosis (notes 5 &amp; 6)</th>
<th>Date antipsychotic first prescribed by a GP (YY/MM) (note 7)</th>
<th>Date antipsychotic last reviewed (note 8)</th>
<th>Is there a stop date recorded (note 9)</th>
<th>Is there a review date recorded (note 9)</th>
<th>Is there a detailed care plan covering the antipsychotics use Yes/No</th>
<th>Is the patient being reviewed regularly by secondary care Yes/No</th>
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Notes
1. Where living 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, audit 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'

October 2015 (reviewed unchanged January 2018) Review January 2020
<table>
<thead>
<tr>
<th>Patient identifier</th>
<th>Gender</th>
<th>Living where (note 1)</th>
<th>If a diagnosis of dementia what type (note 2)</th>
<th>Anti-psychotic type (note 3)</th>
<th>Date antipsychotic first prescribed by a GP (YY/MM) (note 4)</th>
<th>Date antipsychotic last reviewed (note 5)</th>
<th>Is there a stop date recorded (note 6)</th>
<th>Is there a review date recorded (note 6)</th>
<th>Is there a detailed care plan covering the antipsychotics use Yes/No</th>
<th>Is the patient being reviewed regularly by secondary care for behavioural problems Yes/No (note 7)</th>
</tr>
</thead>
</table>

**Notes**

1. Where living 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) or memantine to slow down cognitive decline, the antipsychotic should be reviewed by the GP

October 2015 (reviewed unchanged January 2018)  
Review January 2020
Helping someone with dementia who is distressed or behaving unusually – version 3

There are often good reasons why someone with dementia is distressed or behaving unusually. As you know, the person’s brain is working differently and can affect their normal character and many things on a daily basis. This may include forgetting things, repeating things over and over and misunderstanding what others say. The person might not always be able to tell you what’s troubling them. Sometimes we react to unusual behaviour without knowing how the brain changes have affected the person’s abilities or what they might need or be saying through their behaviour. It can be difficult to work out what the likely cause is and what you can do to help, for the benefit of both of you.

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 website 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. www.alzheimers.org.uk/download/downloads/id/1817/health_and_social_care_professionals.pdf

We know that you have probably tried many things and there is often no ‘right way’ or magic solution. Some approaches work better for some people and situations than others. Also, they may work at one time and not another. It can help to see yourself as exploring what are the most helpful approaches. We have used the ideas of “STOP” and “PAUSE” to describe the key ways to help you listen and watch, to improve your understanding of 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 below, consult your doctor or ask for a referral to your local specialist mental health services, which works with people with dementia and their families.

If you require this document in another format such as large print or audio or in another community language, please contact our Communications Team on 01903 843000
Before you respond… ‘STOP’ and ‘PAUSE’

**STOP**

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

**PAUSE**

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 the guide ‘How to help someone with dementia who is in pain or distress’ on The National Council for Palliative Care website: [www.ncpc.org.uk/sites/default/files/How_Would_I_know.pdf](http://www.ncpc.org.uk/sites/default/files/How_Would_I_know.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. This can lead to changes in behaviour, such as confusion.

**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) or red and hot patches of skin 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. Being dehydrated can lead to further problems.

**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 on the website:* [http://alzheimers.org.uk/factsheet/511](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 bed while awake; use bed for sleep and sex. 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 avoiding 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. 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”?

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. If one is near, 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).
See factsheet on physical activity at:

See factsheet on travelling and going on holiday at:

See booklet on keeping active and involved at:
https://www.alzheimers.org.uk/info/20113/publications_about_living_with_dementia/775/living_with_dementia_-_keeping_active_and_involved

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 every day. Have a quiet time or use calming activity or music, especially at times they are tired, such as after lunch.

**U is for YOU**

**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 yourself and your health and have support. You are not going to get it right all the time. It’s important that you do not take all the responsibility for managing very demanding situations.

**What to do:** Try to share the responsibilities with others and accept help from family, friends, neighbours or professionals. Many people benefit from talking with people in a similar situation. You can find information and support from your local Alzheimer’s Society branch or carers support organisations (contact details at bottom). You can get ideas on how to solve problems or plan for future living arrangements.

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

If you are providing support for someone who cannot manage without it, you are legally entitled to a Carer’s Assessment under the Care Act. This assessment is about your needs and what support you need in your caring role. To seek a Carers Assessment you can call your local Social Care Services or ask someone from Sussex Partnership or your local Carers Centre.

**How do you manage the effects on your relationship?**
Dementia has probably had an enormous impact on your relationship, both in practical and emotional ways. It is normal to want to turn the clock back to how things used to be before the dementia. You may experience changes in your usual roles, talking and sharing together and closeness. You may find some social situations difficult and embarrassing. Some friends may also avoid you. All of these changes can be experienced as a painful loss.

Within your relationship, you may see things differently from each other. One of you is aware of the difficulties and the other may be unaware or does not seem concerned. Dementia can cause people to forget or be unaware of their difficulties as well as how their actions affect others. This is due to brain damage and is not done on purpose. You might have different ways of coping with the dementia. For example, one of you might downplay the difficulties and one of you might be more accepting and open in talking about dementia.

**What to do:** Try to continue with the important things in your relationship, including contact with others. Accept that you might need to take responsibility for looking after both of you. See the changes as the result of the dementia symptoms and the different ways in which people cope. Notice the moments when you are sharing or enjoying things together. Talk about the impact of the loss and changes if you want to. If you need time on your own or with others, having time apart might improve your mood and relationship.
If you want to feel closer together, do things that you can both do, for example life story work. Develop a “life story” together to support reminiscing and conversations. Find Life Story forms at sussexpartnership.nhs.uk or www.alzheimers.org.uk/download/downloads/id/1434/remembering_together_making_a_life_history_book.pdf

Do you understand why they are distressed or behaving out of character for them?
You may struggle to understand someone’s changing behaviour. How you understand the behaviour is crucial to how you will react. If you blame yourself or the person, you are more likely to get angry or frustrated.

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. They may struggle to adjust to the effects of dementia because they cannot maintain the same skills and activities. This can often be expressed through mood changes or unusual behaviours. You may be tempted to do things for the person to help them and to make life easier. This is understandable. However, your intention to make life easier could result in taking away the person’s confidence and independence in doing things themselves. The saying, ‘if you don’t use it, you lose it’, can be true.

What to do: The aims of the following ideas are to support the person with dementia to adjust to the effects of the dementia, to live life as independently as possible and to engage in social and meaningful activities. 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. Keep the flow of conversation going – move on if the person has trouble finding a word or appears anxious. 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.
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 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 from Alzheimer's Society:

*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

**Carers’ Centres**

Information about carers rights, law, emergency respite schemes, carers discount card, carers identification card, employment and information about other local services (i.e. benefits, housing, etc.)

Support as a carer
- One to one
- In support groups, both general and specialised

<table>
<thead>
<tr>
<th>East Sussex</th>
<th>Care for the Carers</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Highlight House</td>
</tr>
<tr>
<td></td>
<td>8 St. Leonards Road</td>
</tr>
<tr>
<td></td>
<td>Eastbourne BN21 3UH</td>
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<tr>
<td></td>
<td>01323 738390</td>
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<td><a href="http://www.cftc.org.uk">www.cftc.org.uk</a></td>
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<td>Twitter and Facebook</td>
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<tr>
<td></td>
<td>Or email: <a href="mailto:sarahg@cftc.org.uk">sarahg@cftc.org.uk</a></td>
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<tr>
<td></td>
<td>0300 777 2011</td>
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<td><a href="http://www.eastsussexyoungcarers.org.uk">www.eastsussexyoungcarers.org.uk</a></td>
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<td>Twitter and Facebook</td>
</tr>
</tbody>
</table>

One to one support and information across the area  
Events and activities  
Opportunity to give feedback to services  
Skills training  
Book club

General Carers Support Groups across the area  
Specialised groups for example  
Mental Health, Learning Difficulties,  
Dementia (Alzheimer's Society)  
Acquired Brain Injury (Headway)

Also:

Young Carers Support (separate team)15-24 years
**Brighton and Hove**

- One to one support and information across the area.
- Events and activities.
- Opportunity to give feedback to services.
- Legal surgeries.
- Meditation group
- Book groups
- Counselling services
- Newsletter

General carer support groups across Brighton and special groups for example:
- Eating Disorders
- LGBT
- BAME
- male carers
- substance misuse
- mental health

Young Carers Support Team (8-25 yrs)
- Boys group
- Sibling group

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**West Sussex**

- One to one support and information across the area.
- Telephone call back service.
- Events and activities.
- Opportunity to give feedback to services.
- Skills training.

General Carers Support Groups across the county
Specialised groups for example:
- Dementia and Mental Health
- Eating Disorders
- Mental Health and Learning Difficulties

Young Carers Support (separate team) 18-25 years

Also

West Sussex Young Carers 5-18 years

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**The Carers Centre**

18 Bedford Place, Brighton
BN1 2PT

01273 746222
email: info@thecarerscentre.org
www.thecarerscentre.org

Twitter and Facebook

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**The Carers Centre**

The Orchard, 1-2 Gleneagles Court, Brighton Road, Crawley RH10 6AD

And

Dove Lodge, 49 Beach Road, Littlehampton BN17 5JG

0300 028 8888

Or email: info@carerssupport.org.uk
www.carerssupport.org.uk

Twitter and Facebook

Call 01903 270300
and ask for the duty worker.

Or email: youngcarers@westsussex.gov.uk
www.westsussex.gov.uk/youngcarers
The Good Sleep Guide for People Living with Dementia

Information for Carers

Causes of Sleep Disturbances

- Changes in 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.

If you require this document in an alternative format, i.e. easy read, large text, audio, Braille or a community language please contact the pharmacy team on 01243 623349 (Text Relay calls welcome).
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.
- Remember the tips from the section above and use them again.
- 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.

April 2013 (reviewed unchanged October 2015 and January 2018) Review January 2020
## 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 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’s sub-type of dementia (ICD-10 category) and Clinician impression of severity of dementia:

<table>
<thead>
<tr>
<th>ICD 10 code</th>
<th>Dementia Sub-type</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
</table>

#### 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.

| 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.

| Depression |
| Anxiety |
| Pain |
| Side effects of current medication |
| Physical illness (constipation, UTI, chest infections, heart failure, etc) |
| Other cause(s) * Please specify |
### Prescribing Antipsychotics for People with Dementia
**Initial Assessment for GPs (continued)**

<table>
<thead>
<tr>
<th>Patient name</th>
<th>Patient’s date of birth</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date of assessment</th>
<th>Practice</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Has there been referral to the Trust guidelines flowchart on managing behaviour problems in patients 65 and over including consideration of non-Antipsychotic medication?  
- Yes
- No

**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.

<table>
<thead>
<tr>
<th>Engagement in social / personal activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes to staff approach (e.g. behavioural approach, distraction techniques)</td>
</tr>
<tr>
<td>Changes to the environment (e.g. lighting, TV, availability of quiet areas, orientation aids)</td>
</tr>
<tr>
<td>&quot;Watchful waiting&quot; / monitoring</td>
</tr>
<tr>
<td>Other approaches (e.g. reminiscence therapy, aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal assisted therapy, massage)</td>
</tr>
<tr>
<td>Other * Please specify</td>
</tr>
</tbody>
</table>

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

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

**Risks and benefits regarding antipsychotic medication discussed with patient or carer?**  
- Yes
- No

- 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 ……………………………………

October 2012 (reviewed unchanged October 2015 and January 2018)  
Review January 2020
### Prescribing Antipsychotics for People with Dementia
#### Medication Review for GPs

<table>
<thead>
<tr>
<th>Patient name</th>
<th>Patient’s date of birth</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Date of assessment</th>
<th>Practice</th>
<th>GP</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Date antipsychotic initially commenced</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotic prescribed</td>
<td></td>
</tr>
<tr>
<td>Dose of antipsychotic currently prescribed</td>
<td></td>
</tr>
<tr>
<td>Date of last antipsychotic review/s (if applicable)</td>
<td></td>
</tr>
</tbody>
</table>

#### Therapeutic response?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please specify improvements noted</td>
<td></td>
</tr>
</tbody>
</table>

#### Adverse events

<table>
<thead>
<tr>
<th>Yes - please detail</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls</td>
<td></td>
</tr>
<tr>
<td>Sedation</td>
<td></td>
</tr>
<tr>
<td>Low blood pressure</td>
<td></td>
</tr>
<tr>
<td>Chest infection</td>
<td></td>
</tr>
<tr>
<td>Anticholinergic side effects (e.g. constipation, blurred vision, urine retention, dry mouth)</td>
<td></td>
</tr>
<tr>
<td>Extra-pyramidal side-effects/Mobility</td>
<td></td>
</tr>
<tr>
<td>Other * Please specify</td>
<td></td>
</tr>
</tbody>
</table>

#### 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?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any dose / drug change? Please specify</td>
<td></td>
</tr>
</tbody>
</table>

#### 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 ………………………………………

October 2012 (reviewed unchanged October 2015 and January 2018) Review January 2020
Responding to Behaviours that Challenge (BPSD) in Older People & Those with Dementia

(Does not cover rapid tranquilisation of acutely disturbed)

**Patient being treated for**

- Schizophrenia, Persistent Delusional Disorder, Psychotic Depression or Bipolar Disorder

No

**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

No

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

In the event of continuing problems, telephone advice can be obtained from the CMHT-OP.

**Note – in the treatment of BPSD, the use of an antipsychotic, (other than risperidone), is an 'off licence' use of the medicine.**

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.

If antipsychotic treatment is indicated: Cautiously consider risperidone as first-line medication for persistent aggression in dementia that is not responsive to non-drug approaches, 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.

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).

Also note that use of antipsychotics in the elderly increases risk of pneumonia by up to 60%.

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.

**Patient has Behavioural and Psychological Symptoms of Dementia (BPSD) causing distress to self and others, eg. delusions, aggression, hallucinations, verbal disruption, disinhibition, apathy and depression.**

Yes

Address potential causes and triggers:

- Physical health incl pain and infection
- Anaemia
- 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

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

No

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. (See NICE Guidance – July 2010).

If antipsychotic treatment is indicated:

- Cautiously consider risperidone as first-line medication for persistent aggression in dementia that is not responsive to non-drug approaches, 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.
- 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).
- Do not use risperidone if patient is on fluoxetine! (Drug interaction fluoxetine increases risperidone levels)
- Other antipsychotics should be avoided wherever possible, but may be considered in low doses.

**Other medication options:**

- Memantine is also a potential treatment option for moderate to severe Alzheimer's Dementia.
- Depression: Consider an antidepressant if clinically depressed. Citalopram (up to 20mg) is first choice if not contraindicated. Sertraline, mirtazapine and trazodone are alternatives. All may help restlessness / agitation.
- Anxiety: Should respond to an SSRI antidepressant longer-term, i.e. citalopram or sertraline, (not fluoxetine!)
- Benzodiazepines should be avoided other than in extreme cases when short-acting lorazepam or oxazepam are less likely to accumulate. Review regularly and monitor closely for worsening confusion, ataxia and falls.
- Poor Sleep: Improve sleep hygiene. If needed, try short-term use of zolpidem or zopiclone.

**IMPORTANT - when reducing or stopping psychotropic medicines, only reduce or stop one at a time.**

Consider reducing or stopping anticholinergic drugs (e.g. procyclidine), tricyclic antidepressants, drugs for urinary incontinence (e.g. oxybutynin) antihistamines (e.g. promethazine), opioids, Parkinson's drugs (e.g. Sinemet), GI drugs (metoclopramide, ranitidine, hyoscine). Acetylcholinesterase inhibitors themselves may sometimes cause agitation. If newly prescribed consider reducing or stopping them to see if behavioural problems resolve.


First published: 1/07. Updated (and approved by Sussex Partnership Drugs & Therapeutics Group): 7/09, 4/12, 7/12, 10/15 (due for review October 18)
Useful contacts, information and website addresses

The Alzheimer’s Society’s information on drugs used to relieve behavioural and psychological symptoms in dementia

https://www.alzheimers.org.uk/downloads/file/2628/factsheet_drugs_used_to_relieve_behavioural_and_psychological_symptoms_in_dementia

The Alzheimer’s Society has a range of other booklets and factsheets to support people living with dementia, carers and healthcare professionals.


The Dementia Action Alliance’s call to action on the use of antipsychotic drugs for people with dementia.

www.institute.nhs.uk/qipp/calls_to_action/Dementia_and_antipsychotic_drugs.html

Social Care Institute for Excellence (SCIE) has a dementia gateway for people who work with people with dementia.

www.scie.org.uk/publications/dementia/index.asp

NHS England and Hardwick CCG have produced a primer for general practice called Dementia Revealed – What Primary Care Needs to Know (2014).


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

www.dementiauk.org

In Sussex there are three carer support organizations that include support for carers of people living with dementia:

West Sussex Carers Support
0300 028 8888
www.carerssupport.org.uk

Brighton & Hove Carers Centre
01273 746222
www.thecarerscentre.org

Carer for the Carers (East Sussex)
01323 738390
www.cftc.org.uk

The London Dementia Strategic Clinical Network has produced: Managing Pain for People with Dementia (2015)

A toolkit: *Dementia Revealed What Primary Care Needs to Know*, has been prepared in partnership by NHS England and Hardwick CCG with the support of the Department of Health and Royal College of General Practitioners.


January 2018 Review January 2020
Acknowledgements

A number of prescribing committees in Sussex and specialist groups in the Sussex Partnership NHS Foundation Trust have contributed to the development of this resource pack over different versions, but particular support was provided by:

General advice:

- Dr Caroline Gorst-Unsworth – Older Peoples Consultant, Sussex Partnership Trust
- Dr Doug Handyside – Older Peoples Consultant, Sussex Partnership Trust
- Dr Stephen Pike – Prescribing Lead, Coastal West Sussex CCG
- Dr Terry Lynch – GP, Mid Sussex
- Richard Rodgers – Lead Pharmacist for Care Home In Reach, Western Sussex Hospitals Trust
- Dr Kim Shamash – Older Peoples Consultant, Sussex Partnership Trust

Initial assessment and medication review forms:

- Dr Nicky Rogan – Older Peoples Consultant, Sussex Partnership Trust
- Jed Hewitt, Chief Pharmacist – Governance and Professional Practice, Sussex Partnership Trust
- Dr Scott Cherry – Older Peoples Consultant, Sussex Partnership Trust

Non-pharmacological approaches to BPSD:

- Jane Shepherd – Consultant Clinical Psychologist, Sussex Partnership Trust
- Claire Hawman, Dementia In-reach Nurse, Sussex Partnership Trust
- Kate Budge, Assistant Psychologist, Sussex Partnership Trust
- Victoria Wray, Team Leader for care Home Reach, Sussex Partnership Trust
- Stephenie Giles, Team Leader for Care Home Reach, Sussex Partnership Trust
- Sally Stapleton, Clinical Psychologist, Sussex Partnership Trust

Advice on pain scales:

- Inge Bateman – Lead Nurse Specialist – Inpatient Pain, Western Sussex Hospitals Trust

Flowchart managing behavioural problems:

- Jane Shepherd – Consultant Clinical Psychologist, Sussex Partnership Trust
- Jed Hewitt, Chief Pharmacist – Governance and Professional Practice, Sussex Partnership Trust

Carers guidance on; ‘Helping someone with dementia who is distressed or behaving unusually’ and ‘Sleep guidance for people living with dementia’:

- Jane Shepherd – Consultant Clinical Psychologist, Sussex Partnership Trust
- Sally Stapleton, Clinical Psychologist, Sussex Partnership Trust
- Carers from Alzheimer’s Society West Sussex carer support groups

Apologies to anyone I may have missed.

Ray Lyon

If you have comments please send them to ray.lyon@sussexpartnership.nhs.uk

January 2018 Review January 2020