Managing Symptoms of Stress and Distress in Dementia

Quick Reference Guide

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Responsible Person	**Care Homes Pharmacist**

With thanks to Shona Mackie and Ann Haugh, NHS Forth Valley, whose flowchart we have adapted.

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NHS Lanarkshire

This guide has been designed to be used by all staff to assist in the management of symptoms of stress and distress in dementia and to eliminate possible causes for changes in emotions, behaviour and functioning. It should be referred to in the first instance, and appropriate assessments/interventions should be carried out prior to utilising psychotropic medicines or referring to Old Age or Learning Disability Mental Health Services (as appropriate). It is accepted that not all interventions will be practical/ suitable in all circumstances.

When reviewing the patient, consider what the potential causes of distress are, for the individual. Consider whether there are underlying unmet needs and how to meet the individual's needs using the flowchart below. Should you require consultation or assistance in considering some of these factors please consider making a referral.

There has been a ***rapid*** change in the patient's behaviour

Exclude Physical Causes

- **Delirium -** check temperature, blood pressure, pulse and bloods e.g. FBC, U&E, LFT, TFT, ESR, CRP, Glucose, Vitamin B12, folate and ferritin levels, MSSU (Use 4AT tool)
- **Dehydration** – check blood as above; especially U&E. Commence on fluid balance chart
- **Pain** – complete appropriate pain assessment tool e.g. Abbey Pain Scale
- **Hunger** – monitor and complete fluid and diet charts
- **Constipation** – monitor bowel habits
- **Tiredness** – chart sleep pattern
- **Medication** – side effects
- **Medication withdrawals –** e.g. benzodiazepines, opiates, antidepressants
- **Sensory Impairment** – sight &/or hearing deficit - refer to sensory impairment service for assessment and advice (where applicable)
- **Hypoxia** – cyanosis, laboured breathing, pre-existing conditions e.g. COPD
- **Recent Stroke**

There has been a ***gradual*** change in the patient's behaviour

Consider Psychological Causes

- **Isolation**, loneliness, lack of meaningful contact with others
- **Feeling anxious,** angry or worried; feeling threatened or vulnerable
- Adjusting to a recent life event or change
- **Depression** – observe for any mood or behavioural changes. Complete appropriate assessment tool
- **Hallucinations** – more commonly seeing and/or hearing things. NB exclude delirium
- **Delusions –** more commonly paranoia and/or suspiciousness. NB exclude delirium
- **Sundowning**- increased agitation and activity occurring in the late afternoon/ early evening

Consider Environmental Causes

- **Noise levels** – over stimulation/elevated noise levels can be antagonistic
- **Lack of social stimulation –** consider appropriate meaningful activities appropriate to capability and needs *(e.g. use Jackie Pool assessment tool)*
- **Inappropriate music** – ensure age related and appropriate to the client group
- **Environment/layout**
  - Is it conducive to the specific patient group?
  - Could it potentially increase confusion and disorientation in people suffering from cognitive impairment?

Consider Other Causes

- **Communication and interactional style of others** – is it tailored to the individual? tone of voice, approach, body language, poor verbal and/or non-verbal communication
- **Inflexible routines** – e.g. toileting, bathing, bedtimes – offer choice
- **Task orientated care**
  - lack of person-centred care
  - not knowing the person
- **Client group**
  -do other individuals trigger behaviours?
- **Continuity of staff**
  - therapeutic relationships
  - team continuity
- **General comfort** – clothing, seating, movement,

If there has been no improvement or further deterioration in the patient's behaviour, consider referral for specialist advice

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Prescribing Notes

It is important to remember that symptoms of stress and distress (also referred to as Behavioural and Psychological Symptoms of Dementia; BPSD) or 'challenging behaviours' in dementia are often a temporary phenomenon or a result of internal and external influences. 'Watchful waiting' and assessment of distress, prior to non-pharmacological interventions should be considered and possible physical causes of deterioration should be ruled out before prescribing antipsychotics.

Any medicines prescribed for symptoms of distress should be prescribed on a short term basis and reviewed regularly. If medication is required for acute distress/ agitation, consider short term use of benzodiazepines prescribed at the lowest effective dose with the rationale for use clearly documented. Where delirium is suspected/ diagnosed, NHS Lanarkshire delirium guidelines should be referred to for prescribing guidance and management.

The use of antipsychotics in adults with dementia should be a last resort after other potential causes of the presentation have been excluded (e.g. physical, psychological or environmental causes - refer to flowchart). It may be appropriate to consider the use of antipsychotic medication if the person with dementia is at risk of harming themselves or others, if they are severely distressed and where there has been an evaluation of the potential risks and benefits of treatment. There is limited evidence to support the use of antipsychotics in managing symptoms of stress and distress. Advice from Old Age or Learning Disability Mental Health Services should be sought if considering an antipsychotic for an adult with dementia. NHSL guidance can be found in the references at the end of this document.

The use of antipsychotic medication in dementia is associated with an increased risk of cerebrovascular events and mortality (the risk of stroke is highest in the first four weeks of treatment). (MHRA Drug Safety Update 2012). Other important adverse effects associated with antipsychotics are; parkinsonism, falls, postural hypotension, constipation, dehydration, chest infections, ankle oedema, deep vein thrombosis/pulmonary embolism and cardiac arrhythmia. Individuals should be kept well hydrated and as mobile as possible to mitigate some of these risks and consideration of potential adverse effects should guide decisions regarding treatment. The use of antipsychotics in Lewy body dementia is associated with greater risks of adverse effects and should generally be avoided. Any decision to use antipsychotic therapy in Lewy Body dementia should be discussed with Old Age Mental Health Services.

Antipsychotics should be commenced at the lowest possible dose, titrated carefully and reviewed within the first four weeks and after 6-12 weeks. At review, discontinuation of the antipsychotic should be considered unless there is significant risk and/or extreme distress. If feasible, an ECG should be carried out prior to starting an antipsychotic and thereafter if clinically indicated.

Risperidone is the only antipsychotic licensed for the treatment of dementia-related behavioural disturbances and then only specifically for short term (up to 6 weeks) treatment of persistent aggression in patients with moderate to severe Alzheimer's dementia unresponsive to non-pharmacological approaches and where there is a risk of harm to the patient or others. The dose for this indication is 250micrograms twice daily, increased according to response in steps of 250 micrograms twice daily on alternate days. The usual dose is 500micrograms twice daily with a maximum dose of 1mg twice daily. In older, frailer adults who are at higher risk of adverse effects, consider a lower starting dose of 250 micrograms once daily (Risperidone liquid 1mg/1ml is recommended for dosing increments of 250mcg as some 500mcg tablets are not scored.)

Continue to consider physical, psychological or environmental causes of presentation during any necessary pharmacological intervention.

Changes to medication must be discussed with the patient if they have capacity. Where capacity is absent and there is an existing legal proxy i.e. welfare attorney or guardian, the decision to prescribe must be discussed with them, risks outlined and agreement sought. If the patient lacks capacity and if there is no formal legal welfare proxy, the principles of the Adults with Incapacity (Scotland) Act 2000 apply and treatment options should be discussed with relevant others, such as next of kin, carer or patient advocate. In either circumstance, an appropriate Section 47 certificate of incapacity is required. If a patient is subject to the Mental Health (Care and Treatment) (Scotland) 2003 Act, check that any psychotropic medication is included on a current T2/T3 certificate.

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Useful resources:

1. NHS Lanarkshire Delirium Guidelines
2. The Abbey Pain Scale: For measurement of pain in patients who cannot verbalise
3. 'Clear Dementia Clear: A Model to Assess and Address Unmet Needs' Dr Frances Duffy, 2019. Jessica Kingsley Publishers, London.
4. 'Understanding Behaviour In Dementia That Challenges: A Guide To Assessment and Treatment', Second Edition. Ian Andrew James. Jessica Kingsley Publishers, London.
5. Pool, J. The Activity Level (PAL) instrument for occupational profiling: a practical resource for carers of people with cognitive impairment. London: Jessica Kingsley, 2012
6. MHRA Drug Safety Update 2012
7. Link to patient info leaflet for use of antipsychotics in dementia;
   http://firstport2/resources/patient-info-leaflets/Documents/PIL.ANTIDE.1519021.L.pdf

   https://www.nice.org.uk/guidance/ng97/resources/antipsychotic-medicines-for-treating-agitation-aggression-and-distress-in-people-living-with-dementia-patient-decision-aid-pdf-4852697005

   https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_drugs_used_to_relieve_behavioural_and_psychological_symptoms_in_dementia.pdf
8. Link to antipsychotic review document
   https://www.nhslcg.scot.nhs.uk/wp-content/uploads/2020/09/Guidance_for_Review_of_Antipsychotic_Prescribing_in_Patients_with_Dementia.pdf

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