Resource Pack for Primary Care

Managing Non-Cognitive Symptoms in People Living With Dementia

Contents

Version 2, January 2023

Introduction

This resource pack has been designed to support primary care professionals and carers across Surrey in optimising the management for people experiencing behavioural and psychological symptoms of dementia (BPSD).

More than 90% of people with dementia will experience BPSD at some time during their illness, particularly in the middle and later stages.

Behavioural symptoms include physical aggression, loud vocalisation, restlessness, agitation and wandering.

Psychological symptoms include anxiety, depressive mood, hallucinations and delusions.

For mild or moderate symptoms, individuals may not experience distress or pose a risk to themselves or others. In such cases, improvement is often achieved in 4-6 weeks without pharmacological treatment. A watchful waiting approach is advocated in such circumstances.

Individuals experiencing these symptoms may not have the legal capacity to make informed decisions about their treatment. In which case care should be taken to ensure this resource pack is used within the context of the Mental Capacity Act 2005.

Emphasis is placed throughout the pack on the recommendation of psychosocial interventions as the first line approach. Referral to the Surrey Dementia Connect service to access the Dementia Navigator service and carer support services should be considered at an early stage.

It is important not to rush into treatment options as many people with BPSD will experience a natural improvement of symptoms over a 4-6 week period. Pharmacological options, in particular antipsychotics, are associated with a number of major adverse outcomes and side effects including extrapyramidal side effects, pneumonia, venous thromboembolism, stroke and death. Any pharmacological treatment should be prescribed for a short course only, with regular review to determine the benefits or otherwise of continuing treatment.

The final pages of the pack include contact details for further advice, support and guidance for both clinicians and carers.

Dementia Connect – to refer to the **Dementia Navigators**
Contactable through https://www.alzheimers.org.uk/get-support/dementia-connect or call **0333 150 3456**
Support line opening hours

- Monday – Wednesday 9:00am – 8:00pm
- Thursday – Friday: 9:00am – 5:00pm
- Saturday – Sunday: 10:00am – 4:00pm

Non-pharmacological Approaches to Managing Behavioural and Psychological Symptoms of Dementia (BPSD)

It is recommended that non-pharmacological approaches are used as a first line approach (Alzheimer's Society, 2021). 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 "BPSD"? – 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 distress and BPSD are given in the left column in the following pages. Use the right column to offer suggestions to care home staff.
- Active involvement of relatives in a person's care is linked to better outcomes
- Consider use of the Positive Behavioural Support plan from Surrey and Borders Partnership NHS Trust (Appendix 5)

If the difficulties 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.

Possible cause: physical health and medication side effects	
BPSD may result from:	**Ideas for carers:**
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 a pain scale, e.g. Abbey Pain Scale (link) 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, dehydration and swallowing difficulties	• Check access to food and fluids and ability to eat and drink independently. Offer support as needed • Consider food and fluid chart to identify patterns and trends. Are they able to eat and drink? e.g. denture pain / mouth ulcers / ability to use cutlery • Are their own dentures available and well fitting, or own teeth in a good state? • Find out personal preferences for food, drinks, crockery etc. – for example, a favourite mug, preferred time to eat a hot meal, prefer food that can be eaten with fingers rather than cutlery. • More information from Dementia UK can be found here • 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, understimulated? • Consider a personalized approach that includes sleep hygiene education, exposure to daylight, exercise, and personalized activities

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? • Is the person using their glasses or hearing aids?
Medication side effects	• Request a review of medication by a pharmacist or GP

Possible cause: environmental factors	
BPSD may result from:	**Ideas for carers**
Understimulation	• Use activities that are personally relevant to interests or previous work • Provide 30 sec - plus spontaneous opportunities for conversations • Social areas to encourage interactions
Overstimulation	• 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 family, carers or staff aware of triggers for BPSD?	• Identify, observe and document triggers and use consistent approach to prevent BPSD • Does BPSD happen after friends or relatives have visited?
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 • Favourite food and drinks • Consistency of 2-3 key workers for most of personal care for first few weeks (check if prefers male/female) • Ensure that established routines are introduced at the earliest opportunity when a person moves from their home to another care setting
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	
BPSD 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 the person believes he/she still has work or care responsibilities, e.g. going to work or needing to collect children from school. • 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, sexual orientation • 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	
BPSD 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 to indicate walking to toilet, etc. • Use picture boards
Hearing and visual difficulties.	• Check for sensory impairment • Check which is their 'best' ear, or if they have visual impairment on one side then approach from the other • Optician / audiology (home visits possible)
Difficulties in recognizing everyday objects	• Use alternative means to aid recognition, e.g. flushing toilet, holding the object, carer to demonstrate use of object
Repetitive behaviours	• Use distraction, reassurance, emotion-focused strategies
Disinhibition • Typically frontal lobe related	• Use distraction techniques and alternative means of meeting needs. • Observe for time of day and notice triggers.
Experiencing delusions and visual hallucinations: symptoms of Lewy Body, Parkinson's disease dementia, vascular or Alzheimer's dementia	• Take personal care tasks slowly and give repeated reassurance about intentions. • Acknowledge the delusion / hallucination – don't ignore or try to prove to the person they are wrong. • If they are not concerned or anxious about it then don't dwell on it. • Ensure plenty of reassurance if person is worried and ensure there are alternative activities to be involved in. • Consider referral to specialist services for further assessment / treatment

Possible cause: underlying emotional or mental health problems	
BPSD may result from:	**Ideas for Carers:**
Undiagnosed depression and anxiety • GP to use Cornell Depression Scale to assess • Depression is a common symptom of all dementias and is often undiagnosed and treated	• Ensure person has access to activities and ACTIVELY encourage participation • Promote active involvement of friends and relatives • 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

RESPONDING TO BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD) IN PEOPLE WITH DEMENTIA

(Does not cover rapid tranquillisation of acutely disturbed people)

Patient with Dementia has **BPSD** causing distress to self and others, e.g. delusions, agitation, aggression, verbal disruption, hallucinations, disinhibition, apathy & depression

Exclude and manage delirium before following the steps below

Check compliance with prescribed medicines. Assess symptoms and optimise treatment for dementia – for people with moderate/ severe Alzheimer's Dementia add in **Memantine** as per NICE guidance. See Surrey PAD and page 12

→ Refer to Dementia Connect (Dementia Navigator) for support for the person and their family or carer.
Consider also a Carers Prescription referral (see Appendix 6 for contact details)

Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to explore possible reasons for their distress. Check for and address clinical or environmental causes (e.g pain, delirium, constipation or inappropriate care). See page 4

BEHAVIOURAL PROBLEMS RESOLVED?

Yes → No indication for medications. Continue non-pharmacological approaches.

No

Use psychosocial interventions as first-line approach to meet unmet needs. Involve Social Care, Community Matron, Dementia Navigator. Include environmental modification, preventative therapeutic activities and formulation-led approaches, (based on functional and behavioural analyses). Actively involve carer / relatives throughout assessment and interventions. See pages 4-8. See Alzheimer's Society resource.

→ Refer to Older Adults Mental Health Services for specialist advice if severe risk to the patient or to others.

ONLY offer medications (short term) to people with dementia who are either at risk of harming themselves or others Or who are experiencing agitation, hallucinations or delusions that are causing them severe distress. Consider using a decision aid to support discussion with the person, their family or carer. (See tool provided by NICE)

→ Identify and treat dominant target symptom groups. See Guidelines for Pharmacological Management of BPSD for treatment options. See page 10

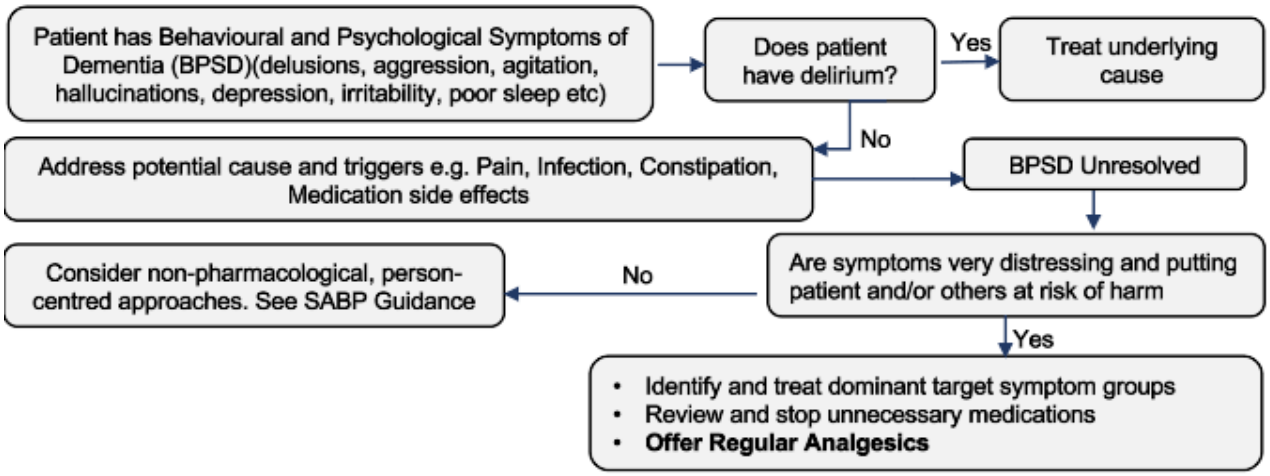
Patient has Delirium. (Short history, <2 weeks, of confusion, hallucination, delusion with fluctuating cognition). GP to treat underlying cause of Delirium

See NICE guidance or local policy

Where a person is being treated for Lewy Body Dementia, Parkinson's disease Dementia, or other non-Alzheimer's dementia - **Refer to / seek advice and guidance from appropriate Specialist**

Where a person is being treated for Schizophrenia, Persistent Delusional Disorder, psychotic Depression or Bipolar Disorder **Refer to appropriate Specialist**

SABP Guidance on Pharmacological Management of Behavioural and Psychological Symptoms of Dementia in Primary Care / Residential Settings

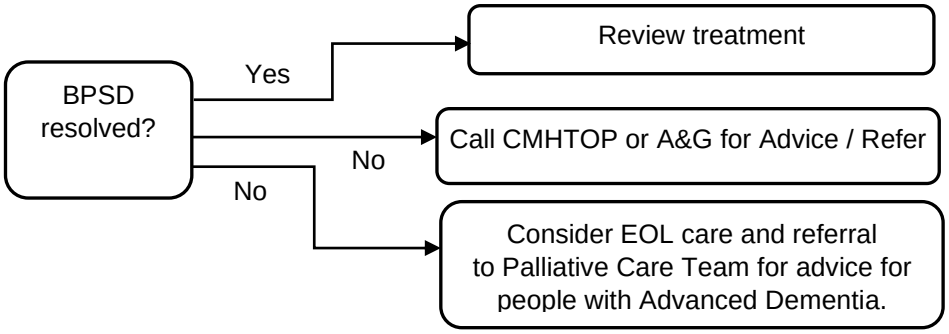


Alzheimer's / Vascular/ Frontotemporal Dementia – NB Ensure use of memantine optimised. See Surrey PAD		
Key symptom Consider discussing with consultant via Advice & Guidance before starting treatment	**First line** *(All drugs listed are Green on the Surrey PAD)*	**Second line**
Depression	Citalopram 10mg - 20mg OD or Sertraline 50mg -200mg OD	Mirtazapine 15mg - 45mg ON
Psychosis	Optimise Memantine (unless contraindicated) Consider Risperidone[S] 250 micrograms BD **after** discussion with Psychiatrist.	*Input from Consultant Psychiatrist via Advice and Guidance*
Aggression	Risperidone [‡] start at 250micrograms BD (up to 6/52 treatment of persistent aggression with risk of harm); refer to Secondary Services	*Input from Consultant Psychiatrist via Advice and Guidance*
Moderate Agitation/ Anxiety	-Consider Regular Paracetamol. Optimise Memantine (unless contraindicated) Citalopram [‡] 10mg – 20mg OD.	Mirtazapine 15-45mg ON; Memantine[S;X] *Input from Consultant Psychiatrist via Advice and Guidance if above not suitable*
Severe Agitation/ Anxiety where risk of harm posed to individual or others caring for them	-Consider regular Paracetamol / Optimise Memantine. Start Risperidone [‡] 250micrograms OD and refer to Secondary Services	Memantine[S; X] *(Input from Consultant Psychiatrist via Advice and Guidance required for memantine without AChEI)*

Dementia with Lewy Bodies or Parkinson's disease dementia - *Discuss management with 2° care*		
Key symptom	**First line**	**Second line**
Depression (If no concerns, may be started without 2° care input)	Citalopram 10mg - 20mg OD or Sertraline 50 - 200mg OD	Mirtazapine 15mg – 45mg ON
Psychosis, aggression, agitation, anxiety or REM Sleep behaviour (nightmares; hyperactivity)	*To be discussed with 2° care before prescribing via Advice and Guidance or Referral via ESR*	
All Dementias: For urgent use in severe agitation only	**Lorazepam 0.5mg BD PRN. Review regularly, at least every 2 weeks.**	

s = Seek advice from Psychiatrist before commencing (A&G via e-Referral Service available)
x = Avoid Memantine in Frontotemporal Dementia as can cause paradoxical agitation. ‡ = Off label indication unless Alzheimers, ensure documented in records

For people not considered to be at an increased risk of suicide, arrange an initial review within 2 weeks. Then review regularly every 4 weeks for the first 3 months. If good response to treatment, consider review every 3 months.
For antipsychotics: Review antipsychotic use at least every 6 weeks and refer to Secondary Care for use beyond 6 weeks.



Please contact Advice and Guidance or CMHT OP (Old Age Psychiatry Team) at any stage for advice

Points to consider when deciding if medication is indicated

- Many people with BPSD will experience significant improvement or resolution of symptoms over a four to six week period.
- Assess pain management and review use of analgesics before considering other options.
- Medication should be prescribed in conjunction with non-pharmacological approaches, not as an alternative to it.
- **ALWAYS** consider renal / liver function, drug interactions and co-morbidities when prescribing
- If antipsychotic treatment is indicated: consider risperidone as first-line medication. Risperidone is licensed for the short-term treatment (up to 6 weeks) of persistent aggression in patients with moderate to severe Alzheimer's disease unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others. When starting risperidone in primary care, ensure that a referral is made to secondary care.
  Note - use of antipsychotics increases risk of extrapyramidal side effects, pneumonia, VTE and stroke. (See Manufacturer's information for full list of side effects).
  If ongoing treatment is recommended by specialist, all involved in person's care should agree that it is the most appropriate approach.
  Use of other antipsychotics would be an off-label indication, supported by advice from secondary care
- Before starting antipsychotics, discuss the benefits and harms with the person and their family members or carers (as appropriate). Consider using a decision aid to support this discussion. (See tool provided by NICE)
- Some commonly used medicines are associated with increased anticholinergic burden and cognitive impairment. Review and minimise the use of such medicines and look for alternatives. There are validated tools for assessing anticholinergic burden (for example, the Anticholinergic Cognitive Burden Scale), but there is insufficient evidence to recommend one over the others. See Appendix 3
- **REFER people being** treated for Lewy Body Dementia, Parkinson's disease Dementia, or other non-Alzheimer's dementia, and people being treated for Schizophrenia, Persistent Delusional Disorder, Psychotic Depression or Bipolar Disorder for review by the Psychiatrist.
- **Suggested Schedule for GPs for Review of Treatment.**

For people not considered to be at an increased risk of suicide:

- Arrange an initial review within 2 weeks.
- Review regularly thereafter — for example, every 4 weeks for the first 3 months or as clinically indicated
- If response is good, consider longer review intervals e.g. every 3 months.

…/contd.

- Review antipsychotic use at least every 6 weeks. After 6 weeks, if treatment is beneficial, ensure involvement of secondary care.
- Review should be undertaken at least every three months to consider whether it is clinically appropriate to continue treatment or to withdraw pharmacological treatment slowly. Short-term prescriptions (maximum 3 months) may be used. Note that antidepressants for depression, anxiety or agitation may be required long-term.

➢ **What symptoms do antipsychotics not help with?**

Antipsychotic drugs do not help with other behaviours such as:

distress and anxiety during personal care
repetitive vocalisations
walking about
social withdrawal
changes in levels of inhibitions

These changes are likely to need personalised non-drug approaches

Prescribing advice – Memantine

Full prescribing information is available via www.medicines.org.uk. See also advice on Surrey PAD Examples of when memantine should be considered: when the dementia is significantly impacting on activities of daily living; there are emerging Behavioural and Psychological Symptoms of Dementia (BPSD); or there is increased carer strain due to deterioration of the person's symptoms of dementia.

Licensed Indication - Memantine is indicated for the treatment of adult patients with moderate to severe Alzheimer's disease.

Monotherapy - The local pathways advise that **memantine MONOTHERAPY** should be initiated or recommended by a specialist and:
- should be offered to patients with severe Alzheimer's disease
- may be used in moderate disease where an AChE inhibitor is not tolerated or contraindicated
- may be used in dementia with Lewy bodies if AChE inhibitors are not tolerated or contraindicated (unlicensed)
- may be used in Vascular dementia ONLY if co-morbid Alzheimer's disease, or dementia with Lewy Bodies (unlicensed)

Combination Therapy - For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor consider memantine in addition to an AChE inhibitor if they have moderate disease and offer memantine if they have severe disease.

Memantine is appropriate for Primary Care initiation when being added to existing AChE inhibitor therapy in patients with worsening cognitive function or other markers of deterioration.

Dosing The maximum daily dose is 20 mg per day. In order to reduce the risk of undesirable effects, the maintenance dose is achieved by upward titration of 5 mg per week over the first 3 weeks as follows:

Week 1 (day 1-7)	*Week 2 (day 8-14)*	*Week 3 (day 15-21)*	*Week 4 onwards*
5mg daily for 7 days	10mg daily for 7 days	15mg daily for 7 days	20mg daily thereafter

Renal or hepatic impairment – maintenance dose

In patients with moderate renal impairment (creatinine clearance 30 – 49 ml/min) daily dose should be 10 mg per day. If tolerated well after at least 7 days of treatment, the dose could be increased up to 20 mg/day according to standard titration scheme.

In patients with severe renal impairment (CrCl 5 – 29 ml/min) daily dose should be 10 mg per day.

No data on the use of memantine in patients with *severe* hepatic impairment are available. Administration of memantine is not recommended in patients with severe hepatic impairment.

Information sources - The manufacturer's information leaflet is available via www.medicines.org.uk. Additional information for people taking memantine is available via the Choice and medication website. This website offers information in different formats and languages. (https://www.choiceandmedication.org/sabp/printable-leaflets/patient-information-leaflets/132/ALL/)

Formulations of memantine other than standard tablets - Memantine is available in tablets of 10 and 20mg. The 10mg tablets can be cut in half to facilitate dose adjustment in steps of 5mg. A liquid preparation (10mg/mL) is available, as are orodispersible tablets (10mg and 20mg) but these are significantly more expensive than the liquid formulation. The use of titration packs containing 5mg, 10mg, 15mg and 20mg tablets to cover the first four weeks of treatment should generally be avoided.

Monitoring of treatment No specific monitoring required

Prescribing advice – Risperidone

Full prescribing information is available via www.medicines.org.uk

Indication - Risperidone is indicated 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. If no effect after 6 weeks, stop treatment. Ensure a referral to the specialist when treatment is started.

The NICE decision aid (link) may be used to help people with dementia, their family/carer make an informed choice about starting treatment.

Off-label use - Treatment should be continued beyond 6 weeks only if there is a clear positive response and all involved in the patient's care are in agreement that it is the most appropriate approach for the individual. If benefit, refer to secondary care for specialist assessment of the behaviour and involvement in decisions re: the need for longer term use.

Dosing - For this indication, a starting dose of 250 micrograms twice daily is recommended.

This dose can be increased, on the advice from the Specialist (Psychiatrist), in steps 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. This website offers information in different formats and languages. (https://www.choiceandmedication.org/sabp/printable-leaflets/patient-information-leaflets/132/ALL/)

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. Orodispersible 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.

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

Baseline –U&Es, FBC, LFTs, Prolactin, lipids (fasting), plasma glucose and HbA1c, ECG, pulse, BP, weight, BMI and waist circumference.

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), plasma glucose and HbA1c, Side effects, ECG, pulse, BP, weight, BMI and waist circumference.

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.

Stopping antipsychotics where prescribed for BPSD

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.

If a decision is made to continue the antipsychotic beyond this first six weeks then future treatment should not be prescribed as repeat medication, but prescribed as an "acute" supply up to a maximum of six weeks. Suggest refer for specialist input.

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.

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.

Antipsychotic prescribed for BPSD	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

For higher doses, reduce gradually over 4 weeks.
NB: If serious adverse effects occur, stop antipsychotic drug immediately.
(taken from the Maudsley Prescribing Guidelines in Psychiatry, 14th Edition)

Appendix 1 - The Abbey Pain Scale

For measurement of pain in patients with dementia and/or learning difficulties who cannot verbalise.

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

Name of person being assessed ……

Name of person completing the scale ……..…

Date ……. **Time** ……..

Last pain relief given was …… **at** ……**(time)**

Q1. Vocalisation e.g. whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3 ☐

Q2 Facial Expression e.g. looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3 ☐

Q3. Change in body language e.g. fidgeting, rocking, guarding part of the body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3 ☐

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

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

Q6 Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injury
Absent 0 Mild 1 Moderate 2 Severe 3 ☐

Add scores for Q1 to Q6 together 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

Acute	Chronic	Acute on Chronic

Abbey J, De Bellis A, Piller N, Esterman A, Giles L, Parker D, Lowcay B. The Abbey Pain Scale. Funded by the JH and JD Medical Research Foundation 1998-2002

Appendix 2 - Carer completed non-cognitive symptom recording form for people living with dementia (Sample)

(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.
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.*

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 3 – 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 multimorbidities taking anticholinergic drugs.
- Review and 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. Consider the benefits and harms of continuing treatment.
- 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.

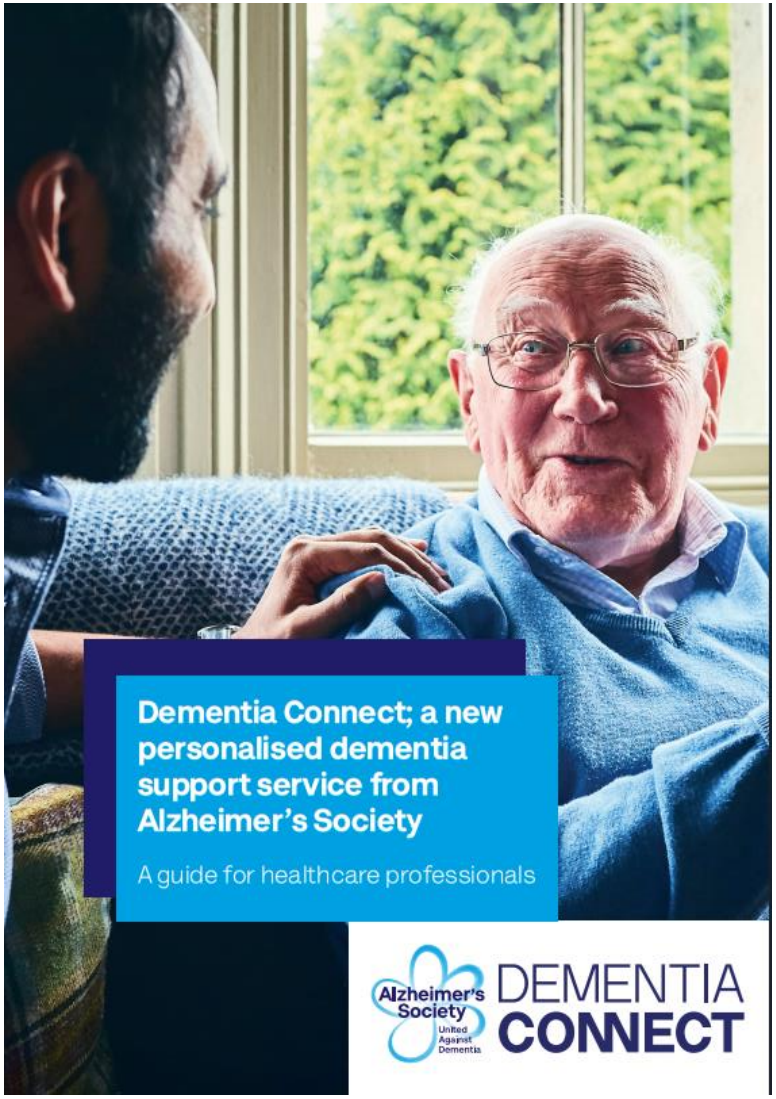
(adapted from PresQIPP B140. Anticholinergic Drugs)

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:
https://www.uea.ac.uk/documents/746480/2855738/Anticholinergics.pdf

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 4 – Dementia Connect information



Dementia support you can trust

As a healthcare professional in your community, you want to do the best for your patients with dementia. At Alzheimer's Society, we do too.

That's why, as the UK's leading dementia charity, we've developed Dementia Connect. A free personalised service that connects anyone affected by dementia to the support they need, when they need it. Not just people with dementia but their carers, family and friends too.

Dementia Connect is endorsed by the NHS Long Term Plan, recognising its role improving dementia care and support alongside other healthcare organisations.

How Dementia Connect can help your patients

We understand that dementia affects everyone differently, so we tailor our support to a patient's individual needs. Our Dementia Advisers provide direct support as well as signposting to other local services. We know it's never easy for a patient to tell their story. That's why we only ever ask them to tell it once.

Support provided can include:

- Advice on how to cope and live with dementia
- Tips for making a home dementia-friendly
- Help navigating social services
- Advice on legal documents and Lasting Power of Attorney
- Connection to dementia groups within local communities

Phone support

Our Dementia Advisers are available on the phone to give the support your patients need. They will offer them the option of regular calls to keep in touch and help meet changing needs.

Support Line Opening Hours *
Monday – Wednesday:
9:00am – 8:00pm
Thursday – Friday:
9:00am – 5.00pm
Saturday – Sunday:
10:00am – 4:00pm

Online Support

Online support is available round the clock through our website. Our online community Talking Point offers anyone dealing with dementia the chance to chat with others in a similar situation. People can read, download and order support materials and search for local dementia services in their area through our dementia directory.

Face to Face Support

Our local Dementia Advisers go out and meet people in the community to offer further support, practical advice and information, from someone who understands what they're going through.

*Calls charged at standard local rate

How you can help

In addition to the care you already offer your patients, we need your help to refer people with dementia, their carers and families to Dementia Connect, so they can get the support they need.

It's easy to register. Go to **alzheimers.org.uk/register** enter your surgery or pharmacy details and you'll receive immediate confirmation of your successful registration. You can register individually or as an entire surgery or pharmacy, all you need is an email address.

You can then start referring patients to Dementia Connect.

Referral to Dementia Connect

If you know someone who would benefit from our support, talk to them about Dementia Connect. They could refer themselves, but to flag particular needs or urgency and be assured that they'll get the support they need, we recommend you make the referral for them.

To make a referral, go to **alzheimers.org.uk/refer** and complete the simple referral form. It only takes a minute or two. Then give the person one of our Dementia Connect referral cards to remind them that we'll be in touch.

Your patient should receive a call from a Dementia Adviser within a week for a full assessment of their needs. In cases of crises or the need for more urgent support, we should contact them within two days.

96%

of people who used Dementia Connect felt the Dementia Advisers provided useful information*

*Dementia Connect User Survey 2019. 164 respondents in the Birmingham and Solihull pilot area

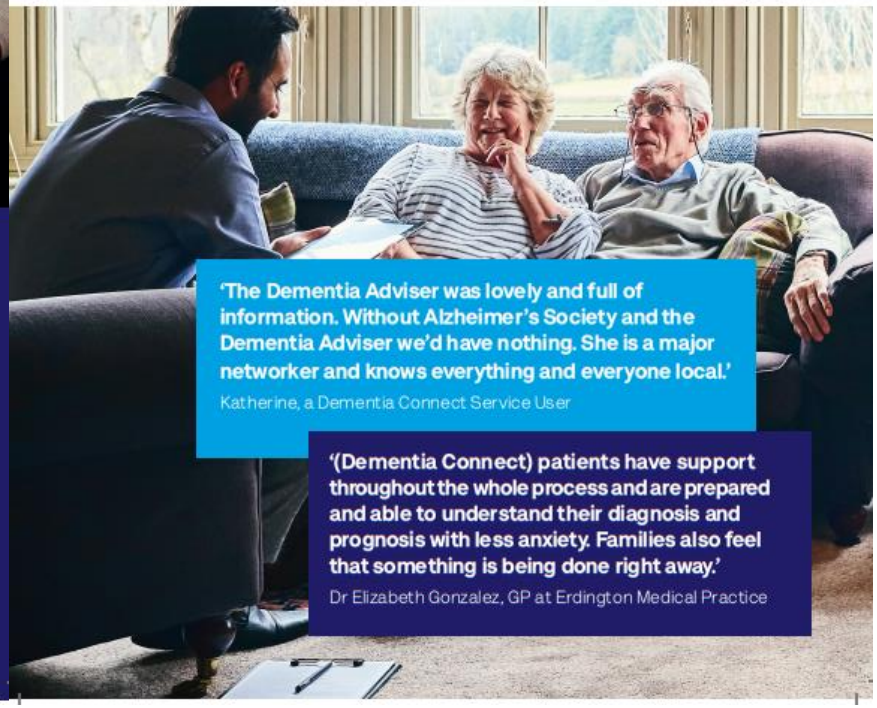
Thank you for your support

You're a crucial part of this support network. With your help, Dementia Connect means your patients are only a phone call or click away from the support they need.

For further information, connect with us:
alzheimers.org.uk/refer
0333 150 3456*

As Dementia Connect is new, parts of the service may not be available in your area just yet.

*Calls charged at standard local rate
Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity no. 296645
DCNDE



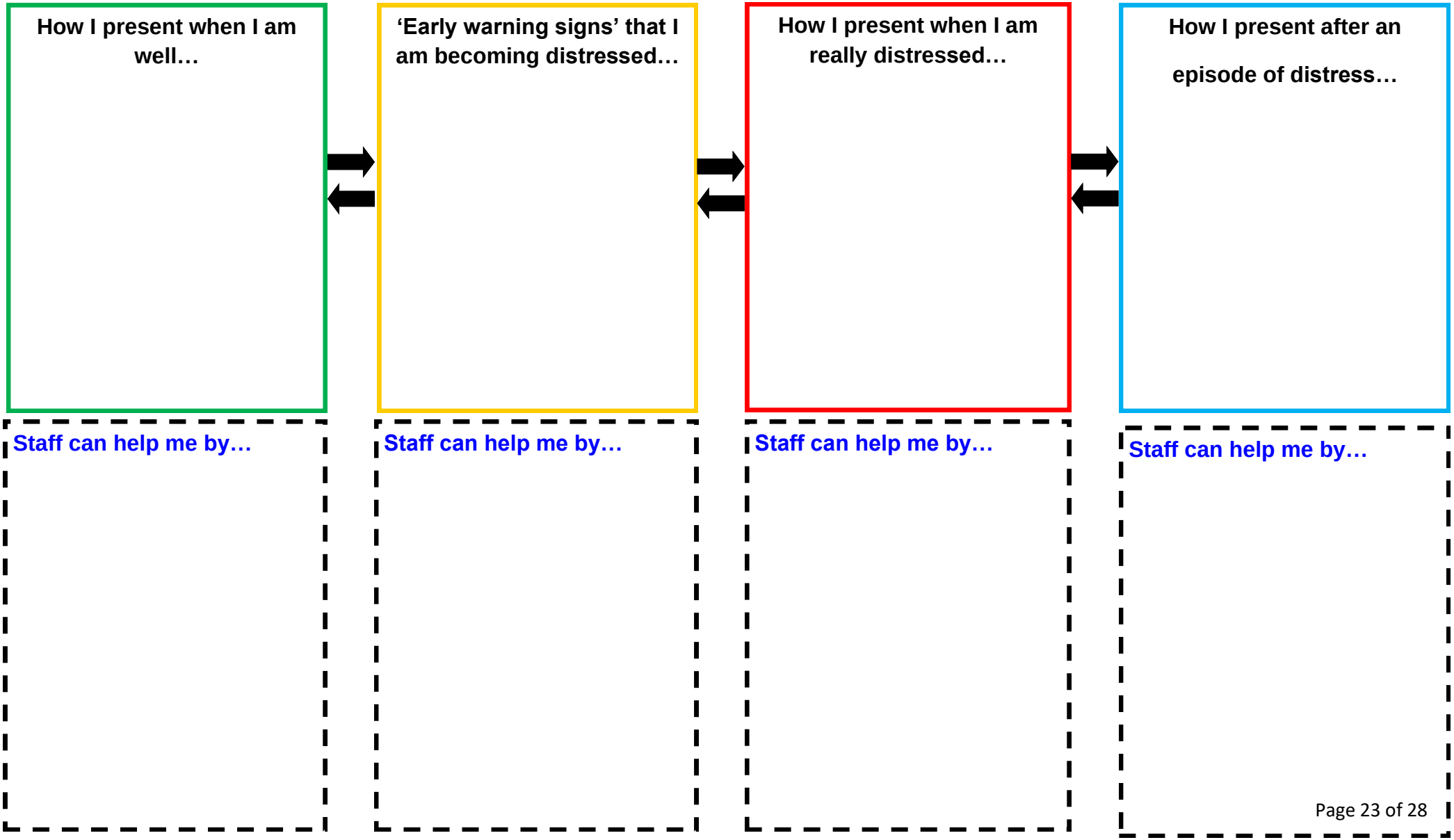
'The Dementia Adviser was lovely and full of information. Without Alzheimer's Society and the Dementia Adviser we'd have nothing. She is a major networker and knows everything and everyone local.'
Katherine, a Dementia Connect Service User

'(Dementia Connect) patients have support throughout the whole process and are prepared and able to understand their diagnosis and prognosis with less anxiety. Families also feel that something is being done right away.'
Dr Elizabeth Gonzalez, GP at Erdington Medical Practice

Appendix 5 – SABP Positive Behaviour Support Plan

Full Name

Positive Behaviour Support Plan



Full Name

All About Me...

Communication tips…

Things that upset or worry me…

PHOTOGRAPH

I like to be called…

Strengths/ things I am proud of…

Important objects/activities that help me cope or calm down...

My preferred *routines*

Things that interest me...

When I say/do this	It usually means,…

Appendix 6 - Further Sources of advice and guidance

For General Practice:

The Local Community Mental Health Team for Older Adults can be contacted by phone or email for advice. Community Services for Older People : Surrey and Borders Partnership NHS Foundation Trust (sabp.nhs.uk)

Advice and Guidance is additionally available through the Electronic Referral Service (ErS) to enable clinicians in primary care to email their local Consultant in the CMHT and request advice and guidance in managing an older person (>65) in primary care without having to make a referral into the service. Please note this is not an emergency or urgent response service and people with immediate risk of harm to self/ others or acute needs should be referred through usual channels.

- Response time is 72 hours.
- This is not a face to face assessment service.

Referrals for older adults are handled by our Single Point of Access (SPA), who will redirect to the appropriate locality team.

To make a referral, GPs and other health professionals should follow the process outlined below:

- GPs should submit referrals to SPA using ErS (Electronic Referral Service)
- Other health and care professionals should email a referral to: spa@sabp.nhs.uk
- GPs and all health and care professionals can 0300 456 8342 to speak to SPA about a referral.

To contact an on call older adults' consultant/registrar (after 5pm Mon-Fri and at weekends and on bank holidays) professionals should call 0300 5555 222.

For Care Homes

Advice and Guidance is available by email for care home staff about mental health issues in the older person living within a care home. Please note this is not an emergency or urgent response service and people with immediate risk of harm to self/ others or acute needs should be referred through usual channels

- Response time is 72 hours.
- This is not a face to face assessment service.

All requests for A&G from Care Home staff should be made through

Mid and East Surrey CMHTOP
CareHomeAdviceandGuidancementalhealth@sabp.nhs.uk

Surrey Heath and North East Hampshire and Farnham CMHTOP
CareHomeAdviceandGuidancementalhealth.SW@sabp.nhs.uk

Northwest Surrey and Guildford and Waverley CMHTOP
CareHomeAdviceandGuidancementalhealth.NW@sabp.nhs.uk

Dementia Connect – Contactable through https://www.alzheimers.org.uk/get-support/dementia-connect or call **0333 150 3456**

Support line opening hours

- Monday – Wednesday 9:00am – 8:00pm
- Thursday – Friday: 9:00am – 5:00pm
- Saturday – Sunday: 10:00am – 4:00pm

- **Alzheimer's Society** Website www.alzheimers.org.uk – contains a wide selection of fact sheets; in particular
  - Changes in Behaviour
  - Challenging Behaviour in Dementia
  - Staying healthy with sleep
  - How to support someone with dementia to sleep better at night
  - "This is me" document
  - When should drug treatments be prescribed for people with dementia?

- **The Carer's Prescription** – A single online referral to ensure carers in Surrey get all the support they need - https://www.actionforcarers.org.uk/for-professionals/general-practitioners/the-carers-prescription/

- Preventing and managing aggressive behaviour - **Action for Carers** is a third sector organization that offers an array of services across Surrey. They can help carers engage in carers assessments, apply for eligible benefits and access support groups. They can also offer peer support. The Carer Helpline is available on **0303 040 1234**. Text on (SMS) **07714 075993.** Send an email to CarerSupport@actionforcarers.org.uk

  - Monday, Thursday, Friday – 9-5pm
  - Tuesday, Wednesday – 9-6pm

- https://dementiaroadmap.info/surrey - The Surrey Dementia Roadmap provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care to support people with dementia and their carers

- **Choice and Medication** – this website provides information leaflets on medicines, and a series of information leaflets on dementia and Alzheimer's disease. https://www.choiceandmedication.org/sabp/

- **Electronic Medicines Compendium** – www.medicines.org.uk – for prescribing information and manufacturer's patient information leaflets

- **Dementia UK** is a charity committed to improving quality of life for all people affected by dementia. http://www.dementiauk.org

- Appropriate prescribing of antipsychotics in dementia. Yorkshire and the Humber Clinical Network and London Clinical Network NHS England https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2022/10/Antipsychotic-Prescribing-Toolkit-for-Dementia.pdf

- Management of dementia in primary care – a module provided by BMJ Learning (https://learning.bmj.com/learning/module-intro/dementia-primary-care.html?moduleId=10032231&searchTerm="dementia"&page=1&locale=en_GB)

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

- NICE Dementia Quality Standard QS184. Published June 2019 https://www.nice.org.uk/guidance/qs184

- NICE. Dementia: assessment, management and support for people living with dementia and their carers. NICE guideline 97. Published: 20 June 2018. www.nice.org.uk/guidance/ng97

- SCIE (Social Care Institute for Excellence) website - https://www.scie.org.uk/dementia/ – fact sheets, online training, training videos

- Surrey Information Point - https://www.surreyinformationpoint.org.uk/ - a directory of care, support and wellbeing services mainly for adults over the age of 25.

- Taylor D, Barnes T, Young A. Maudsley Prescribing Guidelines in Psychiatry. 14th Edition. Wiley Blackwell 2021

See also

- Carrarini C, Russo M, Dono F, *et al*. Agitation and Dementia: Prevention and Treatment Strategies in Acute and Chronic Conditions. *Front Neurol*. 2021;12:644317. Published 2021 Apr 16. doi:10.3389/fneur.2021.644317

- McDermott CL, Gruenewald DA. Pharmacologic Management of Agitation in Patients with Dementia. *Curr Geriatr Rep*. 2019; 8(1):1-11. doi:10.1007/s13670-019-0269-1

- Kales H, Gitlin L & Lyketsos C. Assessment and management of behavioural symptoms of dementia, *BMJ* 2015; 350; h369

This resource pack was based on a document produced by Sussex Partnership NHS Foundation Trust 2018.

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