



Key messages

- Behaviour that challenges (BtC) can be a consequence of a person's unmet health or psychosocial need(s).
- 'Non-pharmacological' approaches are the first-line treatments, rather than psychotropic medications.
- Service pathways for people living at home require different workforce skills and resources compared with those living in 24-hour care settings.

Evidence briefing: 'Behaviour that challenges' in dementia

This briefing outlines the importance of having a psychological understanding of the complex causes of 'behaviour that challenges' (BtC) and related interventions to meet the needs of the person living with dementia. It summarises research and clinical evidence in this arena, to aid commissioners and other stakeholders to shape the service landscape. It is not intended to be read as a set of recommendations for practitioners.

Key messages

- **Behaviour that challenges (BtC) can be a consequence of a person's unmet health or psychosocial need(s).**

BtC can be defined as: 'An expression of distress by the person living with dementia (or others in the environment) that arises from unmet health or psychosocial need(s). The behaviours often reflect attempts by the person living with dementia to maintain a sense of control, dignity and wellbeing, and/or to ease discomfort or distress.'

BtC is referred to in biomedical literature as neuropsychiatric symptoms (NPS) or behavioural and psychological symptoms of dementia (BPSD), giving the false impression that BtC can be treated effectively with medication. However, they often reflect everyday signs of distress, frustration and coping strategies in people who, due to changes in the brain, have to navigate their world using cognitive and sensory information. This can result in unusual or risky behaviour. BtC may also occur when carers and others have difficulty understanding why behaviour happens and as a consequence respond in ways that the person with dementia finds confusing or challenging.

For example, Cohen-Mansfield¹ suggests that BtC often reflects an attempt by a person to signal an unmet need (e.g. to indicate hunger, or to gain relief

from pain or boredom), or an effort by the person with dementia to directly meet their own need (e.g. leave a building to 'go to work' or to 'collect children from school'), or a sign of frustration (e.g. feeling anxious about 'being late for work', or angry at 'being prevented from leaving the building'). In all of these situations the actions are attempts to maintain a sense of wellbeing or to ease distress. For example, a carer's unsuccessful attempts to de-escalate an episode of BtC through reasoning, distraction or restraint may actually lead to frustration and aggression.

People need to be free from discomfort, be treated with dignity² and supported to achieve a sense of control within their lives.

- **'Non-pharmacological' approaches are the first-line treatments, rather than psychotropic medications.**

Perspectives that place behaviour as a symptom of dementia have led to ineffective, inappropriate and sometimes harmful prescribing. The UK government report *Time for Action*³ called for the reduction of antipsychotic use and non-pharmacological effective alternatives as first-line interventions.

These alternatives to treatment focus on finding and resolving the unmet need⁴. Approaches to management take two forms: first, where a BtC has been triggered, effective treatments use

individualised biopsychosocial formulations of need, delivered by skilled practitioners working with family and staff carers^{5,6,7}. Second, preventive person-centred programmes in care homes can cater for an individual's basic needs such as safety, dignity, control, companionship and occupation⁴. For example, many people with mid to late stage dementia require help with intimate care and, for reasons of safety, their freedom may become restricted. By identifying such needs and other potential causes for an individual's distress, unforeseen events of BtC can be reduced. These multi-component approaches also involve training caregivers⁸.

There is good evidence that person-centred approaches reduce the use of antipsychotics in care homes^{9,10,11}. The use of antipsychotics has reduced since publication of *Time for Action* and its associated policies, but the quality of prescribing for antipsychotics and other psychotropic medication is still far from ideal^{7,12}.

Psychological approaches to BtC take into account the variety of potential causes for the behaviour. Psychologists, working alongside other practitioners, are particularly skilled at developing formulations, training staff and supporting effective delivery of interventions to reduce BtC in care homes⁴.

- **Service pathways for people living at home require different workforce skills and resources compared with those living in 24-hour care settings.**

The importance of the caregiving context in BtC was recognised in The NICE-SCIE dementia guidelines (CG 42), where the term BtC was introduced¹³. Caregiving contexts are not the same for those living at home as for those living in care homes or inpatient facilities. Treatment for the former involves working with family members, whereas the latter

involves multiple staff working in complex dynamic systems with each care setting having its own organisational strengths and constraints⁷.

For a behaviour to be perceived as challenging, a 'critical point' must be passed, requiring a judgement by others – usually the family or staff carer. Carers often have different thresholds of when they consider a given behaviour to be challenging. Therefore, the judgement of behaviour can be determined by the perceptions and attributions of others.

Professionals working in specialist mental health community services can fail to recognise the challenges faced by families and staff due to lack of focus on the complexity of delivering interventions for BtC in different care environments, and lack of relevant tools for the bespoke types of interventions required for management of BtC for those living at home compared with those in care homes⁷.

Specialist in-reach care home BtC services in the UK usually draw on the well-known Newcastle formulation-led protocols, which use a 12-week structure for treating BtC, to include six weeks of support for care-plan implementation and bespoke training for staff⁴. The term 'ecopsychosocial intervention'¹⁴ has been used to emphasise the requirement to consider the particular physical and interpersonal environments and the contexts within which dementia care is delivered.

Individually tailored care plans for BtC also take account of the support required by the particular caregiver system^{6,7,11}. Two dementia care quality indicators outline evaluation of evidence of individualised formulated care planning, and for psychosocial intervention as the first line approach, in the management of BtC¹⁵.

Calls to action

- **Use individualised formulations to guide BtC treatment.**

Central to the management of BtC is both ensuring that the needs of the person with dementia are met and resolving any unmet needs using individually formulated biopsychosocial approaches to intervention. It aims to actively treat episodes of BtC and prevent their frequency or escalation. Clinicians and staff working to minimise BtC should be aware of biopsychosocial formulations in which behaviour and associated needs are identified¹⁰.

Calls to action

- Use individualised formulations to guide BtC treatment.
- Ensure appropriate prescribing and monitoring of medications.
- Ensure effective training and supervising of good practices.
- Urgently improve specialist services for people living at home with BtC.

Individually formulated ‘case-specific’ approaches for BtC are the best method for intervening within both family and 24-hour care settings^{5,6,7,16}.

Behavioural observations and associated improved communication between the person with dementia and carer in the management of BtC are also important^{6,16}. Person-centred care is both a philosophy of care and a method of communicating and interacting with the person living with dementia¹⁷.

■ **Ensure appropriate prescribing and monitoring of medications.**

Longer-term sustainability of programmes to maintain the reductions of antipsychotic prescribing remains in the balance¹⁸. Initiatives to regularly review prescribing practices can be combined with reviewing effective non-pharmacological alternatives to the management of BtC using two quality indicators¹⁵ for commissioned services for BtC.

■ **Ensure effective training and supervising of good practices.**

Most formulation approaches involve training and support of family and staff carers^{4,6,8,14}. However, caregiver training is not enough to reduce BtC⁷. On-site regular support is crucial, where carers

require clinical supervision to communicate well with those with dementia, particularly in cases of clinically significant BtC^{7,11,10,19}.

■ **Develop effective ecopsychosocial environments adapted for the needs of the settings.**

Interventions for people living at home have to be designed separately from those living in care homes. The former involve working with family members who have differing motivations, understandings and capacities; the latter involve multiple staff working in complex dynamic systems with each care home having its own organisational strengths and constraints^{7,11}.

■ **Urgently improve specialist services for people living at home with BtC.**

Despite being effective for the management of BtC in family settings⁵, individually formulated interventions remain underused⁵, with a recent NIHR programme⁷ noting that: higher levels of BtC were recorded for those living at home compared with those in care homes; those with clinically significant BtC living at home tended to have milder dementia; and community mental health teams for older people commissioned to provide care to those with mental health problems (including those with dementia and BtC) directed the majority of care towards those without dementia.

Examples of good practice

Example of good practice in inpatient wards

BtC Clinical Link Pathway (CLiP) at Tees Esk & Wear Valley NHS Trust²⁰ adheres to quality indicators for BtC¹⁵ with processes to ensure that every person with dementia on an inpatient ward enters a detailed pathway of care, and none are discharged without a completed formulation and associated care plan. BtC formulations outline the following strategies:

- **Primary preventative strategies** – Ongoing actions occurring to improve quality of life and reduce the likelihood of BtC.
- **Triggers to BtC** – Detailed observations are recorded.
- **Warning signs and BtC** – Observations of how the person may appear just before and during the BtC.
- **Secondary preventative strategies** – Strategies and interventions to avoid the behaviour from occurring or worsening, when warning signs are noticed.
- **Tertiary strategies** – Strategies and interventions to keep the person or others safe during an episode of BtC.

Examples of good practice in care homes

The IDEAS framework to ‘CEASE stress and distress’ in care homes has been implemented by NHS Dumfries and Galloway, Scotland²¹. It demonstrates an eco-psychosocial intervention¹⁴ in practice, summarised as follows:

- C:** Comfort (e.g. review pain, hydration, room temperature).
- E:** Environment (e.g. improve noise, lighting, signage).
- A:** Activity (e.g. facilitate meaningful activity).
- S:** Social contact (e.g. facilitating visitors and other opportunities).
- E:** Engagement (e.g. use emotion-orientated communication).

CLEAR Dementia Care framework at the Northern Health and Social Care Trust, Northern Ireland²²

is a comprehensive formulation programme delivered by a dedicated multidisciplinary team. It serves around 100 care homes across the Northern Trust,

and owing to its success, is working with people living at home and will be working into dementia inpatient settings. Training has been delivered to the other four trusts in Northern Ireland. Since

the implementation of CLEAR, the average length of clinical episodes and number of face-to-face contacts has reduced by over 50 per cent, indicating an earlier reduction in distress.

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