

QUESTIONNAIRE: United Kingdom

1. Assessment of behavioural disorders

1.1 Please specify the different kinds of behavioural disorders which in your opinion need to be assessed:

'Behavioural and psychological symptoms of dementia' (BPSD) include: delusions, hallucinations, depression, anxiety, apathy and a range of behaviours, such as aggression, wandering, disinhibition, agitation, hoarding, sexual disinhibition, and disruptive vocal activity such as shouting.

1.2 Describe the most appropriate approach for this assessment:

A stepped approach

1. Primary care assessment to rule out delirium or delirium in dementia as the cause.
2. Primary care management (including watchful waiting and the provision of advice, education and support for the carer).
3. Where diagnosis of dementia is not established, refer to specialist memory service for diagnosis.
4. Where complicated, refractory to first line treatment, non-self limiting or posing a risk to self or others referral to a specialist community mental health team for older adults led by a consultant old age psychiatrist.
5. Specialist assessment in the home of the person with dementia in the first instance with high reliance on a good collateral history from a family carer (or other)

Please see chapter 8 of the attached NICE/SCIE guideline for further information.

1.3 Describe the most used measurement / assessment tools for these symptoms:

The NPI is most used but this is a research tool in the main.

Older studies have used the BEHAVE-AD.

The CMAI can be useful in research in more severe dementia.

Ad hoc symptom checklists have also been used.

2. Types of home care provision provided by professional carers

2.1 Please describe different approaches to supporting and caring for people with dementia who live at home related to behavioural disorders:

Social care includes:

Home helps/home care workers – these may be generic services for all of specialist dementia services or a mix of both. Please see p46-49 National Dementia Strategy (NDS) attached.

Day care/day hospitals – these may provide direct therapeutic input for the person with dementia and also respite for the carer.

Respite care/short breaks – designed to help carers continue caring, these may be provided in the person with dementia's house with the carer leaving, or in day settings or in care homes. They may last from hours to weeks and may be programmed as part of the care plan or available as an emergency.

Education/carer support – this may be provided by health or social care or the third sector. May be very valuable in preventing subsequent psychological strain and harm to the person with dementia and the carer.

Health care includes:

Primary care – a GP that knows the family and is the co-ordinator and facilitator of specialist care.

Specialist diagnostic services – focussed on early identification and treatment to minimise or prevent BPSD and carer burden. Please see p33-38 NDS.

Specialist community mental health services for older people – teams that can respond to emergencies and help to maintain people in the community using pharmacological and non-pharmacological interventions, supporting carers and primary care. Please see Everybody's Business for service specifications (attached).

2.2 Describe the appropriate non-drug treatment or measures used:

State of the art well summarised in chapters 8 and 9 of the NICE/SCIE dementia guideline.

2.3 In what circumstances is residential / institutional (including hospital) care required?

Hospital:

In a crisis.
 To exclude treatable medical conditions.
 To treat medical conditions
 To enable treatment of refractory BPSD where there is risk of harm to self or others.
 Where placements in residential settings have broken down.

Residential:

When treatment at home is no longer possible or desired.

3. Training programmes / information

3.1 Which kind of information, training and education do exist for people with dementia and their carers?

Very wide range of materials available, they need to be brought together and delivered systematically along with advice and support including that from peers affected by dementia. Please see p38-42 NDS.

3.2 Which are the most efficient dissemination tools for sharing information (for targeting the patients / the carers) and why?

Public information/education campaigns (p24-30 NDS)
 Provision of information at diagnosis (p38-39 NDS)
 A person to contact for advise as the illness progresses (p39-42)
 Primary care settings
 The media
 The internet...

3.3 What training and education programmes do exist for professionals?

Large number of disparate approaches from the highly specialised to generic. The problem is that most people engaged in caring for people with dementia get nothing and do not know they would benefit from such training so do not prioritise this. There is a need for major workforce development that includes undergraduate, postgraduate, vocational and continuing education curricula.