

Guidance for NHS continuing healthcare assessors

Evaluating emotional and psychological needs
for people in the later stages of dementia

Document purpose: This guidance is based on research conducted by the Association for Dementia Studies at the University of Worcester. The research involved a number of key phases including a review of the relevant literature, practice experience from CHC panels, Alzheimer's Society and family carers as well as feedback from nurses who do not have specialist dementia knowledge.

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Target audiences: NHS continuing healthcare assessors including health professionals working in hospitals, staff working in care homes and in the community

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Introduction

Under the National Framework for NHS continuing healthcare (CHC) and NHS-funded nursing care, assessors have a duty to evaluate the needs of a wide range of people in order to determine whether any aspect of their care constitutes a ‘primary health need’. This guidance is designed to help CHC assessors evaluate the emotional and psychological needs of people in the later stages of dementia.

It should be used with the National Framework for NHS continuing healthcare and NHS-funded nursing care (which includes the Decision Support Tool) provided by the NHS continuing healthcare policy team, available at:

www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

The National Framework

All CHC assessors should be familiar with the National Framework. In particular, the following statements outline key principles of the Framework to remember:

- Professional judgement should be exercised in all cases to ensure the individual’s overall level of need is correctly determined. The tool is to aid decision-making in terms of whether the nature, complexity, intensity or unpredictability of a person’s needs are such that the individual has a primary health need.

- The process of assessment and decision-making should be person-centred. This means placing the individual, their perception of their support needs, and their preferred models of support at the heart of the assessment and care-planning process. When deciding on how their needs are met, the individual's wishes and expectations of how and where the care is delivered, and how their personal information is shared, should be documented and taken into account, along with the risks of different types of provision and fairness of access to resources.
- The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS continuing healthcare eligibility.

The National Framework recommends that the Decision Support Tool (DST) should be completed by a multidisciplinary team, and it is worth noting that the National Framework defines a multidisciplinary team as:

- A team of at least two professionals, usually from both the health and social care disciplines. It does not refer only to an existing multidisciplinary team, such as an ongoing team based in a hospital ward. It should include those who have an up-to-date knowledge of the individual's needs, potential and aspirations.

The 12 care domains

The CHC assessment is divided into 12 care domains:

- behaviour
- cognition
- psychological and emotional needs
- communication
- mobility
- nutrition
- continence
- skin integrity (including wounds, ulcers, tissue viability)
- breathing
- drug therapies and medication: symptom control
- altered states of consciousness
- other significant care needs to be taken into consideration.

As a CHC assessor you need to decide the level of need under each domain, in order to make a recommendation as to whether the individual is entitled to NHS continuing healthcare.

Your assessment involves judgement on the nature, intensity, complexity and unpredictability of the individual's needs in each of the 12 domains. If the person you are assessing has dementia, this can have an impact on each of these domains in terms of complicating the complexity and intensity of need.

If the degree of dementia is moderate or severe it is likely that behaviour, cognition, psychological/emotional needs and communication will be compromised and you will need to assess these directly.

If the person you are assessing has co-morbidities in addition to dementia, then their needs under mobility, nutrition, continence, tissue viability, breathing, drug therapy and consciousness can be further complicated by interaction with symptoms of dementia. All domains that are affected should be recorded separately.

Establishing a primary health need

Domains are judged on a six point scale of need:

- no need
- low need
- medium need
- high need
- severe need
- priority need.

However, not all domains are rated across the full range of options.

The domains of behaviour, breathing, drug therapy and altered states of consciousness include levels of need that are so great that they could reach the 'priority' level (which would indicate a primary health need) on their own.

The needs in other domains are not considered ever to be at a level on their own that could trigger eligibility. Needs in relation to cognition, psychological/emotional needs, communication, mobility, nutrition, continence and tissue viability can form part of a range of needs which taken together could constitute a primary health need.

If a need is being well-managed, for example where psychological interventions are meeting behavioural or emotional needs and therefore minimising their impact, then this should still be recorded at the level of need that would be present if the ongoing intervention was withdrawn.

A recommendation of eligibility to NHS continuing healthcare would be expected when there is:

- an identified **priority** need in any one of the four domains that carry this level (behaviour, breathing, drug therapy and consciousness)

- a total of two or more incidences of identified **severe** needs of the seven domains that carry this level (behaviour, cognition, mobility, nutrition, skin, breathing and drug therapy).

The domains of psychological/emotional needs, communication and continence are only ever considered to indicate a high level of need (not priority or severe). These would only contribute to a primary health need if they occurred alongside other needs that were recorded as priority or severe or if there was a combination of a number of domains where needs were identified as high and/or moderate needs.

A combination of needs, which could include even a combination of high and/or moderate levels of need, may indicate a primary health need.

In deciding whether a recommendation of eligibility for NHS continuing healthcare should be made, the overall need and the interactions between needs are taken into account. Where there is a combination of needs in different care domains, evidence from risk assessments is likely to be important.

All judgements need to be based on what the evidence indicates about the nature and/or complexity and/or intensity and/or unpredictability of the individual's needs. Evidence suggesting a strong need in just one of these aspects (nature, complexity, intensity or unpredictability) is enough to indicate a primary health need.

If you are in any doubt as to the level of need that should be recorded, or you have any concerns, speak with your colleagues in order to obtain appropriate advice and assistance.

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The impact of dementia

Assessing the needs of someone in the later stages of dementia is not an easy task, particularly when you have not known the person over a prolonged time period. As a CHC assessor you are asked to ensure that the individual you are assessing and their carers or representatives understand and agree to what has been written.

If you are being asked to assess a person living with dementia in a care home it is likely (although not always the case) that the person you are assessing will not be able to give you a first-hand account of their needs. Often the person you are assessing may lack the mental capacity to understand and agree to your assessment.

You will need to use your observation skills and weigh up evidence from the person themselves, carers, staff and previous assessments and records. You will then have to use your professional judgement in order to come to a decision. This guide is based on best practice and evidence in order to help you with your decisions.

Psychological and emotional needs

Understanding the psychological and emotional needs of people with dementia can be difficult. Research into this area is increasing, however there are some misconceptions that are commonplace. Remember the following key facts:

Lack of capacity to make informed decisions does not mean lack of capacity to experience distress

Research suggests that people living with advanced dementia have a preserved capacity to process emotions, and they are able to recognise expressed emotions in others and react to others on an emotional level (Tariot, 2003). Individuals who lack capacity may be unable to make informed decisions, and may lack insight into their own condition, but this does not mean that they are incapable of experiencing emotional wellbeing or illbeing.

People with advanced dementia feel pain and distress but they may have difficulty telling you about this directly

It is important not to make assumptions about an individual's emotional and psychological needs based on the fact that they have dementia. People in the later stages of dementia and/or with high levels of cognitive impairment are still able to experience depression and distress, regardless of whether they are able to communicate this verbally.

Emotional distress may be communicated as behavioural disturbance

Around 90 per cent of people with dementia experience what is known as behavioural and psychological symptoms of dementia (BPSD). Sometimes these are also called neuropsychiatric symptoms

(NPS) or referred to as challenging behaviour or behaviours that challenge. These behaviours include, but are not limited to, withdrawal (Kverno et al, 2008), aggression and agitation (Cohen-Mansfield et al, 2012).

It is important to remember that these behaviours can be an expression of unmet emotional needs or symptomatic of a general health problem. For example, the person may be in physical discomfort due to hunger or pain (Testad et al, 2010). It is essential that the underlying cause of BPSD is explored, by investigating the areas listed in section 3, Questions to consider (see pages 14–17), or seeking advice and input from colleagues and family members, where appropriate. This will help you to identify whether these behaviours are the result of emotional distress, or another factor or combination of factors.

People in the later stages of dementia do not become withdrawn and disengaged just because they have cognitive impairment

It is important that disengagement is not dismissed simply as a result of cognitive impairment. Many people with advanced dementia may become withdrawn or disengaged as a behavioural response to distress (Kverno et al, 2008), and thus withdrawal could be a key sign that someone is experiencing depression or anxiety. If an individual appears withdrawn, it is essential that a thorough investigation is conducted into the potential cause of the withdrawal, using the same methods outlined above – considering the questions listed in section 3 (see pages 14–17) or talking to colleagues and family members, where appropriate. Don't simply dismiss the issue as an inevitable part of cognitive impairment.

Depression can occur for the first time at any age

Depression can occur at any age, and a significant number of people experience depression for the first time in later life. Life stresses that are inherent in growing older have been implicated in increasing vulnerability to depression (Alexopoulos, 2005). It is therefore important that people with dementia who exhibit symptoms associated with depression are assessed appropriately in order to ensure that depression does not go undiagnosed simply because the individual has no documented past history of depression.

Depression is common in dementia

Studies have shown that depression commonly occurs in people with all degrees of cognitive impairment (Enache et al, 2011; Volicer et al, 2012) with an estimated prevalence of 17–35 per cent for people with advanced dementia (Boller et al, 2002). People with dementia who experience depression are more likely to express distressed behaviours, including BPSD (Prado-Jean et al, 2010), as the presence of behaviours that challenge could be a sign of depression.

It is important to recognise that individuals with any type of dementia and at any stage of the condition are at risk of depression (Enache et al, 2011; Volicer et al, 2012), and so it is essential that appropriate assessments are undertaken to ensure that depression is not overlooked for individuals with advanced dementia.

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Questions to consider

There are a number of key questions that could and should be considered when assessing an individual with dementia, particularly if they are unable to communicate verbally.

Below is a list of prompts that may help you to assess an individual with dementia. This is by no means an exhaustive list and you may find that there are additional questions and queries that you need to raise when completing an assessment.

These prompts are useful to consider at all stages of the assessment, including in discussions with the person with dementia, family members and care staff and when investigating written records and notes. Some of the prompt questions listed have been adapted from areas identified in other sources. Where this is the case, the author or article is indicated below.

Indicators of depressed mood

If the person is very withdrawn and apathetic it may be that they have an underlying depression or physical condition that is contributing to this. The following questions can help to assess whether this is the case and whether the care team have considered this as an explanation.

- Has there been a change in the person's normal sleeping or eating routines (eg reduced or increased appetite, insomnia or over-sleeping)?
- Has the person lost weight?
- Does the person get pleasure from anything?
- Does the person appear apathetic?
- Does the person show appropriate facial expressions in response to stimuli (eg do they smile back at a friendly face)?

- Has an appropriate scale for assessing depression in people with dementia been completed? (Examples of scales are listed in Appendix 2)
- Has the person got physical health problems that could be causing sleep disturbance, weight loss or apathy?
- Is the person being prescribed medication that could be causing appetite and sleep disturbance?

Indicators of hallucinations

If the person is perplexed or agitated it may be that they are experiencing hallucinations or disturbed perceptions or thoughts. This may be triggered by the neurological impairment associated with the dementia or by an environmental cue that is being misinterpreted. It may also be because of an underlying physical condition causing delirium. The following questions can help to assess whether this is the case and whether the care team has considered this as an explanation.

- Is there any evidence of auditory or visual hallucinations?
- If yes, how do these hallucinations present:
 - Is the person grabbing or picking at things in the air, or trying to pick things up from the floor or other surfaces that aren't really there?
 - Does the person appear to be listening or talking to somebody that isn't there?
 - Does the person appear to be looking at somebody who isn't there?
- How often do hallucinations occur? Do they occur at particular times of the day or night?
- How long do the hallucinations last for? Are the hallucinations responsive to changes in the physical environment, such as changes in lighting?
- What is the level of distress caused by the hallucination?

- Can the person be reassured or distracted from distress caused by the hallucinations?
- Has the person recently experienced a period of physical ill-health (infection, high temperature) that could have triggered hallucinations?
- Has the person got appropriate and functioning spectacles and hearing aids?
- Is the person being prescribed medication that could be causing visual disturbance?

Indicators of anxiety and distress

If the person is often anxious or distressed there may be a pattern that can help the care team to understand the underlying cause of the distress. Look out for triggers such as environmental factors or the actions of staff or residents that are misinterpreted. These errors could be caused by neurological impairment or an underlying physical condition. The following questions can help to assess whether this is the case and whether the care team have considered this as an explanation.

- Does the individual show any signs of anxiety or distress? If yes:
 - How long do periods of anxiety/distress last?
 - How often do periods of anxiety/distress occur?
 - How severe are the periods of anxiety/distress? (E-learning for Healthcare, 2012)
- How does the person present during periods of anxiety/distress?
 - Does the person shout or call out? If yes:
 - How often?
 - What do they call out?
 - Does the person exhibit facial expressions or body language that suggest anxiety or distress (eg turning away, shifting uncomfortably, reaching out for physical contact from a trusted family member or other individual)?
 - Is it likely that the cause of the distress might be untreated pain?

Indicators of responsiveness to reassurance

It is important to assess how the team supports the emotional wellbeing of residents. Skilled care can make a big difference to the level of distress people will experience, so much so that sometimes the actual distress is very short-lived. However, if skilled care is not in place the person may well revert to longer periods of distress. Consider the following prompts to help assess this.

- How does the individual react to their surroundings?
- Does the individual participate in daily activities and care planning? (E-learning for Healthcare, 2012)
- If the person becomes distressed, how do staff react?
- What intervention does the person need when they become distressed?
- Is there a plan of care in place to manage disturbed mood/hallucinations or distress?
 - Does this have an impact on the person's behaviour?
 - Are there any triggers that can precede a period of anxiety/distress (eg does the person become distressed when family or friend visitors leave)?
 - Does the individual respond to reassurance? (E-learning for Healthcare, 2012)
 - If the individual responds to reassurance, how long does it take to reassure the person until they are calm and settled?

When assessing the psychological and emotional needs of a person with dementia, it is important to consider the environment that they are in, as this may contribute to their symptoms. For example, someone could feel disorientated and distressed in a hospital setting but this distress may be alleviated when they are in a more familiar environment to them.



Making the assessment

In accordance with the National Framework, the person you are assessing, along with their perceived support needs and preferences, should be at the heart of the assessment process.

You should meet them first to try to gain their consent to complete the assessment. If you are unsure whether the person has capacity to give their consent, this should be determined using the Mental Capacity Act 2005 and the associated code of practice. You will need to record how the person with dementia (or their representative) contributed to the assessment and, if they could not be involved, why this was.

It is important for you to spend some time with the person and observe them yourself. This may help to verify or clarify comments from care staff or family members and notes in care plans. If you can, it is a good idea to arrange multiple assessment visits and spend time with the person at different times of the day during different activities. This can be particularly useful in assessing whether the psychological and emotional needs are responsive to reassurance or different approaches.

Communicating effectively

When assessing someone with significant cognitive disability you should ensure that your non-verbal communication conveys warmth and consideration. If your body language or facial expression shows annoyance or scrutiny, this is what a person with dementia will notice, even if the words you are using express something very different. Piecing together fragmented speech and summarising what you have heard back to the person with dementia can be helpful to assist with understanding.

When someone is unable to communicate using language, there is a reliance on non-verbal communication such as touch, holding, stroking, eye contact and smiles to help the person feel at ease with your presence.

Pay careful attention to the behaviour of the person with dementia to assess how the person is feeling. You may be able to pick up on non-verbal indicators that can be immensely helpful when assessing an individual's emotional and psychological needs.

Some non-verbal indicators of emotional distress are listed below. Many of these are identified in the article Difficulties in identifying distress and its causes in people with severe communication problems (Regnard et al, 2003):

- changes in breathing patterns (particularly an increased rate of breathing or unusually noisy breathing)
- body tension
- fidgeting
- repetitive vocalisation
- crying
- searching for family members to seek comfort
- wringing hands or squeezing a blanket or other object
- facial expression (eg grimacing, wide eyes, clenching teeth etc).

On the other hand, the following may be signs of emotional and psychological wellbeing:

- relaxed open posture
- social responsiveness
- signs of pleasure at other people and surroundings
- initiation of contact, seeking eye contact, smiling at others
- singing, humming along to music
- joining in with activities, approaching other people
- sense of humour, laughter.

Evidence from others who know the person well

Family members

Family members can often be one of the best sources of information, as they know the person's past history and personality well. It can be useful to try and talk to the person and family members separately, as it may be the case that family members often don't give a full picture of what's going on because they don't want to upset the person by giving their opinion and observations in front of them. Additionally, the person themselves may not want to comment on certain things (such as negative psychological and emotional symptoms that they are experiencing) because they don't want to upset or worry their family.

However, this is not to say that there are not potential benefits in meeting with the family member and person together. It may be helpful to see how the individual mood is when their family is present and it may be that the person is more open or feels more comfortable to discuss things with the support of their family.

Care staff

Obtaining the observations of a variety of care staff involved can be very helpful. Care assistants and activity co-ordinators may have had more opportunity than nursing staff to spend time with the person and thus they may be able to offer more insight into how they are on a day-to-day basis. For example, care staff may be able to offer insight into whether the person can get pleasure from things, potential triggers for any periods of distress, or whether the individual appears to be constantly worried, frightened or upset.

When asking other professionals for their opinions about the needs of the individual, it is important to try and obtain the views of staff who have spent a significant amount of time with the person, and also to gain multiple perspectives, where possible.

Other forms of evidence

As well as speaking to the person with dementia themselves, professional carers and family members, there are a number of sources that can provide evidence in order to help with an assessment of psychological and emotional needs. However, it is important to note that assessments should be based on accurate and up-to-date information. Care plans and patient notes that are outdated may not be a reliable source of information. It is important to consider the quality, reliability and validity of every source of evidence that is explored.

Past history

In some instances, people who have had long-standing mental health problems may be experiencing these again in the context of dementia. Look for any records that the person with dementia has previously experienced:

- depression
- anxiety
- psychosis
- admissions to hospital for any of the above
- past or current prescriptions for psychotropic medication.

Records should indicate whether the person's psychological and emotional state has recently changed or that this is a long-term condition. This needs to be balanced with not labelling people just because they have had a psychiatric diagnosis in the past.

Medication records

Is the person currently being prescribed medication for depression or anxiety? Have they been prescribed these in the past and they have been discontinued?

Has the person been prescribed any medication that may be causing them to appear apathetic, drowsy or with a reduced appetite? If this is the case then signs of depression that you have observed may be due to medication. Likewise, some medication can increase arousal and agitation.

Also, be aware that people with dementia who have experienced BPSD in the past may have been prescribed antipsychotic medication that may have caused over-sedation. Again, this may make the person appear particularly withdrawn and unresponsive. No one should be on antipsychotic medication for longer than 12 weeks without a review. If in doubt, refer to a pharmacist or GP for advice.

Behavioural charts

Examining behavioural charts can be helpful in identifying patterns of behaviour and may enable a better understanding of someone's current emotional state and any potential triggers for anxiety or distress.

Care plans

Is there any mention in the care plans of low mood, anxiety and distress or hallucinations? Are there strategies in place to try to manage these?

Risk assessments

Are there any risk assessments for suicide or self-harm within the notes?

Mental health assessments

Has the mental health liaison team or community psychiatric service been involved in this person's care and are there reports you can draw on? Check whether specific assessment scales (eg to assess depression or anxiety) have been completed, such as the Geriatric depression scale or Cornell scale for depression in dementia. Some additional tools are listed at the end of this guide.



Recording the correct level

You need to show evidence of how you have considered psychological needs and their impact on the individual's health and wellbeing. You should detail how this contributes to the overall care needs and include underlying causes of any distress you note.

You have to describe the actual needs of the individual with particular attention to the frequency and intensity of need, unpredictability, deterioration and any instability. You then need to ascribe an overall level of need as described in the table shown in Appendix 1.

When making complex decisions about an individual's needs, it can be beneficial to discuss cases with colleagues, particularly those with a mental health background who have more expertise in assessing psychological need. The National Framework states that if, after considering all the appropriate evidence, it is difficult to decide on the level of need to record, you should choose the higher of the levels under consideration and record the evidence relating to the decision alongside any significant differences of opinion.

References

Alexopoulos, GS (2005). Depression in the elderly. *Lancet*, 365(9475), 1961–1970. doi:10.1016/S0140-6736(05)66665-2.

Boller, F, Verny, M, Hugonot-Diener, L and Saxton, J (2002). Clinical features and assessment of severe dementia. A review. *European Journal of Neurology*, 9(2), 125–136. Available at: www.ncbi.nlm.nih.gov/pubmed/11882053 [Accessed 16 Dec 2014].

Cohen-Mansfield, J, Thein, K, Marx, MS, Dakheel-Ali, M and Freedman, L (2012). Efficacy of nonpharmacologic interventions for agitation in advanced dementia: a randomized, placebo-controlled trial. *The Journal of Clinical Psychiatry*, 73(9), 1255–1261. doi:10.4088/JCP.12m07918.

E-learning for Healthcare (2012). Assessment prompts for completing a DST (2012 Version). Available at: www.e-lfh.org.uk/projects/continuing-healthcare [Accessed 16 Dec 2014].

Enache, D, Winblad, B, and Aarsland, D (2011). Depression in dementia: epidemiology, mechanisms, and treatment. *Current Opinion in Psychiatry*, 24(6), 461–472. doi:10.1097/YCO.0b013e32834bb9d4.

Guaita, A, Malnati, M, Vaccaro, R, Prezatti, R, Marcionetti, J, Vitali, SF and Colombo, M (2009). Impaired facial emotion recognition and preserved reactivity to facial expressions in people with severe dementia. *Archives of Gerontology and Geriatrics*, Suppl.1, 135–146. Available at: <http://medcontent.metapress.com/index/A65RM03P4874243N.pdf>

Kverno, K, Rabins, P, Blass, D, Hicks, K and Black, B (2008). Prevalence and treatment of neuropsychiatric symptoms in hospice-eligible nursing home residents with advanced dementia. *Journal of Gerontological Nursing*, 34(12), 8–17. Available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC2828146/ [Accessed 16 Dec 2014].

NHS Herefordshire Clinical Commissioning Group (2009). London Health Needs Assessment.

Prado-Jean, A, Couratier, P, Druet-Cabanac, M, Nubukpo, P, Bernard-Bourzeix, L, Thomas, P, Clément, JP (2010). Specific psychological and behavioral symptoms of depression in patients with dementia. *International Journal of Geriatric Psychiatry*, 25(10), 1065–1072. doi:10.1002/gps.2468.

Regnard, C, Mathews, D, Gibson, L, and Clarke, C (2003). Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing*, 9(4), 173–176.

Tariot, PN (2003). Medical management of advanced dementia. *Journal of the American Geriatrics Society*, 51, s305–s313.

Testad, I, Auer, S, Mittelman, M, Ballard, C, Fossey, J, Donabauer, Y, and Aarsland, D (2010). Nursing home structure and association with agitation and use of psychotropic drugs in nursing home residents in three countries: Norway, Austria and England. *International Journal of Geriatric Psychiatry*, 25(7), 725–731. doi:10.1002/gps.2414.

Volicer, L, Frijters, DHM, and Van der Steen, JT (2012). Relationship between symptoms of depression and agitation in nursing home residents with dementia. *International Journal of Geriatric Psychiatry*, 27(7), 749–54. doi:10.1002/gps.2800.

Level of need	Description	Evidence
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Moderate need	Mood disturbance, hallucinations or anxiety symptoms, or periods of distress that do not readily respond to prompts and reassurance and have an increasing impact on the individual's health and/or wellbeing.	From observation/ interview
	or Due to their psychological or emotional state the individual has withdrawn from most attempts to engage them in care planning, support and/or daily activities.	From family
		From staff
		From records

High need	Mood disturbance, hallucinations or anxiety symptoms, or periods of distress that has a severe impact on the individual's health and/or wellbeing.	From observation/ interview
	or Due to their psychological or emotional state the individual has withdrawn from any attempts to engage them in care planning, support and/or daily activities.	From family
		From staff
		From records

Is emotional and psychological distress a complicating factor in communication, mobility, nutrition, continence, tissue viability ?	From observation/ interview
	From family
	From staff
	From records

Appendix 2: Tools/scales

The following tools are validated measures that can be used to help inform a decision around emotional and psychological needs for a person with dementia.

Tool name and abbreviation	Description	Link/reference
Behavioral pathology in Alzheimer’s disease rating scale (BEHAVE-AD)	25-item scale to measure behavioural and psychological symptoms, rated on a 4-point scale of severity. Also includes a global rating and free response section at the end. Designed for completion by a rater following an interview with the caregiver.	Reisberg, B, Auer, SR and Monteiro, IM (1996). Behavioral pathology in Alzheimer’s disease (BEHAVE-AD) rating scale. International Psychogeriatrics, 8, Suppl. 3. http://supp.apa.org/books/Making-Evidence-Based-Psychological-Treatments-Work-With-Older-Adults/appendix6.4.pdf

Tool name and abbreviation	Description	Link/reference
The Bradford wellbeing profile	An observational tool that can be used to aid assessments of social and emotional needs of people with dementia, through focusing on a number of positive and negative behavioural indicators defined in the guidelines.	Bradford Dementia Group (2008). The Bradford wellbeing profile. Bradford: University of Bradford. www.bradford.ac.uk/health/media/healthmedia/Bradford-Wellbeing-Profile-with-cover-(3).pdf
Challenging behaviour scale (CBS)	25-item rating scale, designed for completion by care home staff following resident observations. Focuses on incidence, frequency and difficulty managing resident behaviour.	Moniz-Cook, E, Woods, R, Gardiner, E, Silver, M and Agar, S (2001). The challenging behaviour scale (CBS): Development of a scale for staff caring for older people in residential and nursing homes. <i>British Journal of Clinical Psychology</i> , 40, 309–322.

Tool name and abbreviation	Description	Link/reference
Cohen-Mansfield agitation inventory (CMAI)	29-item rating scale, designed for completion by a trained researcher interviewing nursing home staff/ caregivers. 29 agitated behaviours are rated on a 7-point frequency scale.	Cohen-Mansfield, J, Marx, MS and Rosenthal, AS (1989). A description of agitation in a nursing home. <i>Journal of Gerontology: Medical Sciences</i> , 44(3), 77–84. www.dementia-assessment.com.au/symptoms/CMAI_Manual.pdf
Cornell scale for depression in dementia (CSDD)	19-item scale, designed for completion by a rater following observation and separate interviews with the person with dementia and a caregiver. Rates signs and symptoms of depression of a 3-point scale in terms of severity. Designed for assessment of people with dementia who are able as a minimum to communicate their basic needs.	Alexopoulos, GS, Abrams, RC, Young, RC and Shamoian, CA (1988). Cornell scale for depression in dementia. <i>Biological Psychiatry</i> , 23(3), 271–284. www.health.vic.gov.au/older/toolkit/07Cognition/03Depression/docs/Cornell%20Scale%20for%20Depression%20in%20Dementia-Review-Depression.pdf

Tool name and abbreviation	Description	Link/reference
Cohen-Mansfield agitation inventory (CMAI)	29-item rating scale, designed for completion by a trained researcher interviewing nursing home staff/ caregivers. 29 agitated behaviours are rated on a 7-point frequency scale.	Cohen-Mansfield, J, Marx, MS and Rosenthal, AS (1989). A description of agitation in a nursing home. <i>Journal of Gerontology: Medical Sciences</i> , 44(3), 77–84. www.dementia-assessment.com.au/symptoms/CMAI_Manual.pdf
Dysfunctional behaviour rating instrument (DBRI)	22-item scale, designed for completion by a caregiver. Rates behaviours on two 6-point scales, to measure frequency and how problematic the behaviour is.	Molloy, DW, McIlroy, WE, Guyatt, GH and Lever, JA (1991). Validity and reliability of the dysfunctional behaviour rating instrument. <i>Acta Psychiatrica Scandinavica</i> , 84, 103–106. www.von.ca/english/Caregiving/CaregiverManual/Guideline/Tools/Tool%20J%20-%20CARES%20Program%20Tools/Tool%20J7.pdf

Tool name and abbreviation	Description	Link/reference
Neuropsychiatric inventory (NPI)	<p>12-domain scale to assess psychopathology and neuropsychiatric symptoms. Designed for completion by a rater following a caregiver interview. Rates behaviour on a 4-point scale of frequency, a 3-point scale of severity and a 5-point scale of caregiver distress.</p>	<p>Cummings, JL, Mega, M, Gray, K, Rosenberg-Thompson, S, Carusi, DA and Gornbein, J (1994). The neuropsychiatric inventory: comprehensive assessment of psychopathology in patients with dementia. <i>Neurology</i>, 44(12), 2308–2314.</p> <p>www.dementia-assessment.com.au/behavioural/NPI.pdf</p>
Rating anxiety in dementia scale (RAID)	<p>18-item scale, designed for completion by a rater following checks of clinical notes and interviews with the patient and caregiver. Rates signs and symptoms of anxiety on a 4-point scale in terms of severity.</p>	<p>Shankar, KK, Walker, M, Frost, D and Orrell, M (1999). The development of a valid and reliable scale for rating anxiety in dementia (RAID). <i>Aging and Mental Health</i>, 3, 29–49.</p> <p>http://discovery.ucl.ac.uk/136552/</p>

Tool name and abbreviation	Description	Link/ reference
Revised memory and behaviour problems checklist (RMBC)	24-item measure, designed for completion by the caregiver. Measures memory difficulties, depression and disturbance.	<p>Teri, L, Truaz, P, Logsdon, R, Zarit, S and Vitaliano, PP (1992). Assessment of behavioural problems in dementia; the revised memory and behavior problems checklist. <i>Psychology and Aging</i>, 7, 622–631.</p> <p>www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/memory-behavior.aspx</p>

Notes

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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