

Chapter 4

Functional assessment

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Key points

- The functional assessment plays a key role in the diagnosis of dementia.
- Cognitive decline may have a direct impact on activities of daily living.
- Questions about changes in daily life are usually more reliably answered by a family member, close friend or co-worker.
- If information about daily activities is not available or cannot be reliably addressed, a visit to the person's home may be required.



General background

A thorough functional assessment plays an important role in the diagnosis of dementia as it not only determines a person's ability to manage their everyday needs but can also highlight whether there are concerns regarding their safety. Cognitive decline may have an impact on activities of daily living. This may range from leisure activities (playing card games), instrumental tasks (taking medication or paying bills on time) and basic activities (cooking, dressing, and grooming). People with cognitive complaints will be asked about changes in their daily life which may be directly related to the cognitive decline but can also be associated to other medical conditions altering muscle strength, vision, mobility, and more. Additional factors that may further complicate functional abilities are changes in behaviour, as well as the availability of adequate social and physical support in the person's environment, especially for individuals who live alone. Questions about changes in daily life are usually more reliably answered by a family member or a close friend, a neighbour and sometimes even by a work colleague. The assessment should be based on activities or tasks that the person used to do well that may have recently changed or declined.

“ People experiencing cognitive decline tend to minimise their impairments.

A decline in activities of daily living is a key component to the definition of dementia and requires clinical judgment to assess its significance; changes may be subtle and occur only in leisure activities. Some activities may have never been done before due to cultural or gender constraints, or there was no opportunity to perform them. One of the reasons family members or friends, referred to clinically as 'informants' when on a questionnaire, need to be asked about activities of daily living is that people experiencing cognitive decline tend to minimise their impairments. As some carers, particularly spouses, may also be in denial, it is recommended to seek as much input as possible from additional family members and/or friends, whenever possible.

Personal safety becomes of significant concern with an individual with cognitive decline due to their inability to perform certain tasks. Various rooms within the home, outdoor spaces or the workplace can increase the risk of falls and injuries. Kitchen appliances such as stoves, ovens, microwave ovens and toasters as well as barbeques have a high fire risk if used inappropriately. Bathrooms, bedrooms, and homes with many stairs can increase the risk of falls if anti-slip mats, handlebars, properly secured carpets and night lights are not installed. The inability to administer one's own medication, mistaking cleaning products for food or grooming supplies, as well as losing the ability to properly use utensils such as knives, scissors and razors can cause serious injury.

Another important concern regarding the impact of cognitive decline revolves around the complex topic of driving. Despite the person with dementia's capacity to recall their route, driving requires a tremendous number of quick reflexes and reactions and good peripheral vision, which decline as the condition progresses. Such things as differentiating the brake and gas pedals, recognising road signs, adhering to crossings, changing traffic colour lights, and the sudden appearance of cyclists and pedestrians require significant cognitive and visual awareness.

Financial vulnerability is another consequence of cognitive decline. A person may lose the ability to pay their bills on time, make random purchases, misuse credit and

debit cards, as well as become victims of financial fraud via phone and email scams. Protecting the financial assets of a person with cognitive decline becomes of paramount importance that could involve multiple steps including obtaining a power of attorney or protection mandate.

Assessing a person's ability to drive and manage personal finances are two of the most delicate topics a healthcare professional will need to address as these are directly linked to maintaining an individual's independence. Any recommendation made that specifies that an individual can no longer perform one of these tasks needs to be delivered with compassion.

The functional assessment process involves completing a semi-structured questionnaire or a structured scale before or during the medical appointment. If information about initiation, planning and effective performance of daily activities is not available or cannot be reliably assessed, a visit to the person's home may be required by an occupational therapist, social worker or other qualified healthcare professional.

Examples of activities of daily living scales are listed in Table 1 below and some are critically reviewed in the expert essay by Dr. Isabelle Gélinas.

Table 1. Examples of activities of daily living scales

Alzheimer's Disease Cooperative Study – Activities of Daily Living Inventory (ADCS-ADL)	Galasko D, Bennett D, Sano M, Ernesto C, Thomas R, Grundman M, et al. An inventory to assess activities of daily living for clinical trials in Alzheimer's disease. The Alzheimer's Disease Cooperative Study. <i>Alzheimer Dis Assoc Disord.</i> 1997; 11 (Suppl 2): S33–9.
Amsterdam IADL Questionnaire	Sikkes SAM, de Lange-de Klerk E, Pijnenburg YAL, Gilissen F, Romkes R, Knol DL, Uitdehaag BMJ, Scheltens P: A new informant-based questionnaire for instrumental activities of daily living in dementia. <i>Alzheimer's Dement</i> 2012; 8: 536–543.
Bristol Activities of Daily Living Scale	Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. <i>Age and Ageing</i> , 25, 113–120.
Disability Assessment in Dementia (DAD)	Gelinas I, Gauthier L, McIntyre M, Gauthier S: Development of a functional measure for persons with Alzheimer's disease: the disability assessment for dementia. <i>Am J Occup Ther</i> 1999; 53:471–481.
Functional Activities Questionnaire (FAQ)	Pfeffer RI, Kurosaki TT, Harrah CH Jr, et al. Measurement of functional activities in older adults in the community. <i>J Gerontol.</i> 1982; 37:323–329.
Functional Assessment Staging (FAST)	Reisberg, B (1988) Functional assessment staging (FAST). <i>Psychopharmacol Bull</i> , 24, 653–659.
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)	Jorm AF. A short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): Development and cross-validation. <i>Psychol Med</i> 1994; 24(1):145–153.
Interview for deterioration in Daily living activities in Dementia (IDDD)	Teunisse, S., Derix, M. M., & van Crevel, H. (1991). Assessing the severity of dementia. Patient and caregiver. <i>Archives of Neurology</i> , 48,274–277.
Nurses' Observational Scale for Geriatric Patients (NOSGER)	Spiegel R, Brunner C, Ermini-Fünfschilling D, Monsch A, Notter M, Puxty J, Tremmel L.J. (1991) A new behavioural assessment scale for geriatric out- and in-patients: the NOSGER (Nurses' Observation Scale for Geriatric Patients). <i>Am Geriatr Soc.</i> 39(4):339–47.
Progressive Deterioration Scale (PDS)	DeJong R, Osterlund OW, Roy GW. Measurement of quality-of-life changes in patients with Alzheimer's disease. <i>Clin Ther.</i> 1989; 11:545–54
Physical Self-Maintenance and Instrumental Activities of Daily Living (PSMS & IADL)	Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. <i>Gerontologist.</i> 1969;9(3 pt 1):179–186.

There is no perfect scale, but as previously indicated, having a structured approach based on clinical needs when asking about daily tasks is most beneficial. The short form (16 items) of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) may be particularly useful to clinicians as it compares a person's current cognitive

and functional abilities and those abilities from ten years ago. It can also be completed prior to the medical assessment (1). The IQCODE short form appears below in Table 2. It is available online in its original version as well as in multiple languages.

Table 2. Informant questionnaire on cognitive decline in the elderly (iqcode) short form

Now we want you to remember what your friend or relative was like 10 years ago and to compare it with what he/she is like now. 10 years ago was in 20___. Below are situations where this person has to use his/her memory or intelligence and we want you to indicate whether this has improved, stayed the same or got worse in that situation over the past 10 years. Note the importance of comparing his/her present performance with 10 years ago. So if 10 years ago, this person always forgot where he/she had left things, and he/she still does, then this would be considered 'Hasn't changed much'. Please indicate the changes you have observed by circling the appropriate answer. Compared with 10 years ago, how is this person at: 1 2 3 4 5

- 1. Remembering things about family and friends e.g. occupations, birthdays, addresses**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 2. Remembering things that have happened recently**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 3. Recalling conversations a few days later**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 4. Remembering his/her address and telephone number**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 5. Remembering what day and month it is**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 6. Remembering where things are usually kept**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 7. Remembering where to find things which have been put in a different place from usual**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 8. Knowing how to work familiar machines around the house**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 9. Learning to use a new gadget or machine around the house**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 10. Learning new things in general**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 11. Following a story in a book or on TV**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 12. Making decisions on everyday matters**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 13. Handling money for shopping**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 14. Handling financial matters e.g. the pension, dealing with the bank**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 15. Handling other everyday arithmetic problems e.g. knowing how much food to buy, knowing how long between visits from family or friends**
Much improved – A bit improved – Not much change – A bit worse – Much worse
- 16. Using his/her intelligence to understand what's going on and to reason things through**
Much improved – A bit improved – Not much change – A bit worse – Much worse

Expert essay

Assessing functional performance in activities of daily living in individuals with Alzheimer's disease

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Decline in the ability to perform daily activities is a predominant characteristic of Alzheimer's disease, which significantly impacts the quality of life of the affected individuals and their family members (1). It is a diagnostic criterion for Alzheimer's disease. The rate of decline in the performance of activities of daily living is also used to monitor disease progression and is a strong predictor of institutionalisation (2). Evidence suggests that decline in complex activities of daily living may be a predictor of conversion to dementia (3). The assessment of functional performance in activities of daily living is therefore a vital component of

the diagnostic process as well as the care planning for individuals with Alzheimer's disease regarding decisions about intervention and the suitable level of care required. Functional measures of performance in daily activities usually include basic self-care or self-maintenance activities such as dressing, bathing and eating, and instrumental activities of daily living such as managing finances, cooking or household chores. These activities are key for determining a person's ability to live independently and to identify the level of assistance or care required. More advanced activities such as work and leisure are sometimes included.

As cognitive function deterioration appears to account for only some of the functional activity changes in Alzheimer's disease, clinicians should not solely rely on cognitive test results to predict functional performance. (4). Measures of functional ability in activities of daily living allow for the identification of tangible real-life difficulties experienced daily by people with Alzheimer's disease. These provide more meaningful answers for them and their family members. It is recommended to opt for functional measures that have been specifically developed or tested on people with Alzheimer's disease as they incorporate criteria that evaluates activities affected by the disease process and demonstrate progressive decline in functional performance if it occurs.

In a clinic setting, functional performance is evaluated using various methods, each drawing on different sources of information. These include self- or informant- reported measures as well as performance-based ones through direct observation. Each approach can offer valuable insight. This essay will focus on informant-based questionnaires which are quickly and easily administered, allow for the assessment of a wider range of activities and a comparison with previous levels of functioning. Self-reported measures can be more problematic to use as awareness of their own abilities may be impaired due to disease progression. Performance-based instruments, though they provide a more objective viewpoint of functional decline, are limited by the number of listed activities frequently engaged in and are more time-consuming to implement. A selection of informant-based questionnaires are currently available for use, and none have been singled out as the best option from the reviews that have been conducted to date (5–7). Choosing a measure that is suitable for clinical practice becomes complex. Several criteria should be considered when deciding on an applicable activities of daily living assessment for use.

An important criterion to consider is the population for whom the measure is intended, accounting for the severity of the disease (mild, moderate or severe) and the living environment (community or institution). We know there is a continuum of functional decline over the course of the disease. Decline occurred earlier in the more complex instrumental activities of daily living as they require greater cognitive organisation, while progressive changes in the more overlearned basic self-care activities were observed in later stages. Therefore, for the assessment of individuals with mild Alzheimer's disease, functional measures should include more complex parameters of instrumental activities of daily living. Notably, research findings support the inclusion of topics on financial management, telephone use, medication intake, transportation usage and consumption of everyday technology in the evaluation of individuals in the early stages of the disease (6). The Amsterdam IADL Questionnaire© (8) is an example of a measure which incorporates these types of activities. On the other hand, for residents of long-term care facilities, instruments

including basic activities for daily living would be more appropriate, such as the Bristol Activities of Daily Living Scale, which has been used with nursing home residents with advanced dementia (9). However, to follow individuals with Alzheimer's disease and track changes over time, an instrument that includes a range of activities from complex to more basic would be preferable.

The proposed use and the quality of the instrument in terms of psychometric properties should also be considered. An important property to consider is the questionnaire's validity. Does it truly measure the functional status of activities of daily living? Are the important dimensions or components needed to identify problematic activities of daily living abilities in Alzheimer's disease included? For instance, if the questionnaire is to be used as a diagnostic tool, it will need to include activities that can also identify functional limitations in individuals affected by the disease. Again, instruments should include complex to basic activities affected by the disease over time. If the intent is also to determine a level of care or to guide intervention, it may be useful to select a questionnaire that provides parameters for the type of assistance, a description of how the activities are performed or areas of deficits which may impair functional performance. For example, the Disability Assessment for Dementia (DAD) (10) includes a range of basic and instrumental activities of daily living that are known to progressively decline over the course of the disease. These are examined in relation to executive functions, which are found to be a strong predictor of independent functioning in Alzheimer's disease (11). The reliability of the measure or the extent to which it is exempted from measurement error should also be considered. Should the questionnaire be administered by more than one person, steps must be taken to ensure that the results would be the same and not be influenced by the rater (inter-rater reliable). Measure reliability is also essential when used to monitor progress over time and is administered on more than one occasion (test-retest reliability). Sensitivity to meaningful or clinically important change (responsiveness) is another important property if the questionnaire is used to measure the impact of an intervention over time.

Other factors to consider when using a functional questionnaire include practicality and cultural relevance. Practicality entails the time required to administer the questionnaire and the related burden on both the clinician and informant when it consists of many questions that are complex to score. Costs and the need for intensive training may also influence the choice of questionnaire. Cultural relevance is particularly significant when an instrument was developed in another country and was subsequently translated. Information on how the instrument was adapted to account for culture-specific topics is needed, as well as assurances that the translated version underwent a cross-cultural validation. For example, in the Disability Assessment for Dementia (10), which was translated in more

than 55 languages, certain items such as choosing appropriate utensils for feeding needed to be adapted for countries where eating is performed without the use of cutlery.

Assessments of functional performance in activities of daily living provide important information to determine a person's ability to live independently in the community.

Several questionnaires are available for people living with Alzheimer's disease. To select the best measure to use in their practice, clinicians should consider the instrument's intended purpose, psychometric properties, practicality and cultural validity.

References

1. Andersen CK, Wittrup-Jensen KU, Lolk A, Andersen K, Kragh-Sørensen P. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. *Health Qual Life Outcomes* [Internet]. 2004 Sep 21 [cited 2021 Jul 8];2. <https://pubmed.ncbi.nlm.nih.gov/15383148/>
2. Gaugler JE, Duval S, Anderson KA, Kane RL. Predicting nursing home admission in the U.S: A meta-analysis. *BMC Geriatr* [Internet]. 2007 [cited 2021 Jul 8];7. <https://pubmed.ncbi.nlm.nih.gov/17578574/>
3. Luck T, Riedel-Heller SG, Luppá M, Wiese B, Bachmann C, Jessen F, et al. A hierarchy of predictors for dementia-free survival in old-age: Results of the AgeCoDe study. *Acta Psychiatr Scand* [Internet]. 2014 Jan [cited 2021 Jul 8];129(1):63–72. <https://pubmed.ncbi.nlm.nih.gov/23521526/>
4. Mlinac ME, Feng MC. Assessment of Activities of Daily Living, Self-Care, and Independence. *Arch Clin Neuropsychol*. 2016 Sep 1;31(6):506–16.
5. Kaur N, Belchior P, Gélinas I, Bier N. Critical appraisal of questionnaires to assess functional impairment in individuals with mild cognitive impairment. *Int Psychogeriatrics* [Internet]. 2016 Sep 1 [cited 2021 Jul 8];28(9):1425–39. <https://pubmed.ncbi.nlm.nih.gov/27072886/>
6. Jekel K, Damian M, Wattmo C, Hausner L, Bullock R, Connelly PJ, et al. Mild cognitive impairment and deficits in instrumental activities of daily living: A systematic review. *Alzheimer's Res Ther*. 2015;7(1).
7. Sikkes SAM, De Lange-De Klerk ESM, Pijnenburg YAL, Scheltens P, Uitdehaag BMJ. A systematic review of Instrumental Activities of Daily Living scales in dementia: Room for improvement. *J Neurol Neurosurg Psychiatry* [Internet]. 2009 Jan [cited 2021 Jul 8];80(1):7–12. <https://pubmed.ncbi.nlm.nih.gov/19091706/>
8. Sikkes SAM, De Lange-De Klerk ESM, Pijnenburg YAL, Gillissen F, Romkes R, Knol DL, et al. A new informant-based questionnaire for instrumental activities of daily living in dementia. *Alzheimer's Dement* [Internet]. 2012 Nov [cited 2021 Jul 8];8(6):536–43. <https://pubmed.ncbi.nlm.nih.gov/23102123/>
9. Boyd PA, Wilks SE, Geiger JR. Activities of Daily Living Assessment among Nursing Home Residents with Advanced Dementia: Psychometric Reevaluation of the Bristol Activities of Daily Living Scale. *Heal Soc Work* [Internet]. 2018 May 1 [cited 2021 Jul 8];43(2):101–8. <https://pubmed.ncbi.nlm.nih.gov/29554326/>
10. Gélinas I, Gauthier L, McIntyre M, Gauthier S. Development of a functional measure for persons with Alzheimer's disease: The disability assessment for dementia. *Am J Occup Ther* [Internet]. 1999 [cited 2021 Jul 8];53(5):471–81. <https://pubmed.ncbi.nlm.nih.gov/10500855/>
11. Marshall GA, Rentz DM, Frey MT, Locascio JJ, Johnson KA, Sperling RA. Executive function and instrumental activities of daily living in mild cognitive impairment and Alzheimer's disease. *Alzheimer's Dement*. 2011 May 1;7(3):300–8.
12. Jorm AF. A Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Iqcode): Development and Cross-Validation. *Psychol Med* [Internet]. 1994 [cited 2021 Jul 8];24(1):145–53. <https://pubmed.ncbi.nlm.nih.gov/8208879/>

Conclusions

A comprehensive functional assessment has a dual purpose: to determine a person's ability to manage their everyday needs and validate concerns about their safety and independence. Major areas of concern are the risks associated with falls or injuries, driving and financial vulnerability.

Cognitive decline can certainly impact a person's activities of daily living and people with these complaints will be asked about the symptoms they are experiencing. However, clinicians are also encouraged to use a semi-structured questionnaire as a diagnostic tool to discuss with a person's partner, family member or friend. In this way, clinicians will gain reliable insight into the changes observed over time and compare previous and current abilities. These daily living activities can range from basic, leisure or instrumental tasks. Should another person be unavailable, a visit to the person's home may be warranted to obtain additional information. An important motivating factor is to assess whether a person can safely continue to live independently at home.

There are several informant-based questionnaires available and criteria for use should include the population being measured, the severity of the disease and the living environment. As well, one must consider which daily activity topics from basic to complex are included, psychometric properties of validity and reliability of the measurement tool, areas of deficit that may impair functional performance, practicality and cultural relevance.

Choosing to use a semi-structured cognitive assessment tool to evaluate a person's activities of daily living and demonstrate progressive decline provides meaningful and necessary information to a person living with dementia and their family members.