SPECIAL REPORT

# Indications and expectations for neuropsychological assessment in routine epilepsy care: Report of the ILAE Neuropsychology Task Force, Diagnostic Methods Commission, 2013–2017[1]

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## Summary

**The International League Against Epilepsy (ILAE) Diagnostic Methods Commission charged the Neuropsychology Task Force with the job of developing a set of recommendations to address the following questions: (1) What is the role of a neuropsychological assessment? (2) Who should do a neuropsychological assessment? (3) When should people with epilepsy be referred for a neuropsychological assessment? and (4) What should be expected from a neuropsychological assessment? The recommendations have been broadly written for health care clinicians in established epilepsy settings as well as those setting up new services. They are based on a detailed survey of neuropsychological assessment practices across international epilepsy centers, and formal ranking of specific recommendations for advancing clinical epilepsy care generated by specialist epilepsy neuropsychologists from around the world. They also incorporate the latest research findings to establish minimum standards for training and practice, reflecting the many roles of neuropsychological assessment in the routine care of children and adults with epilepsy. The recommendations endorse routine screening of cognition, mood, and behavior in new-onset epilepsy, and describe the range of situations when more detailed, formal neuropsychological assessment is indicated. They identify a core set of cognitive and psychological domains that should be assessed to provide an objective account of an individual's cognitive, emotional, and psychosocial functioning, including factors likely contributing to deficits identified on qualitative and quantitative examination. The recommendations also endorse routine provision of feedback to patients, families, and clinicians about the implications of the assessment results, including specific clinical recommendations of what can be done to improve a patient's cognitive or psychosocial functioning and alleviate the distress of**

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[1]This report was written by experts selected by the International League Against Epilepsy (ILAE) and was approved for publication by the ILAE. Opinions expressed by the authors, however, do not necessarily represent the policy or position of the ILAE.

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**any difficulties identified. By canvassing the breadth and depth of scope of neuropsychological assessment, this report demonstrates the pivotal role played by this noninvasive and minimally resource intensive investigation in the care of people with epilepsy.**

**KEY WORDS: Epilepsy, Neuropsychology, Training, Minimum standards, Adult, Pediatric.**

The role of neuropsychology in the assessment and treatment of people with epilepsy is constantly evolving in response to new classifications of the disorder; rapid advances in neuroimaging and genetic techniques; the development of new treatments; and improved understanding of the nature, timing, and causes of cognitive problems. At a meeting held in Washington, D.C. in December 2013, members of the ILAE Diagnostic Methods Commission asked the Neuropsychology Task Force to create and disseminate recommendations to answer the following questions:

1 What is the role of a neuropsychological assessment?
2 Who should do a neuropsychological assessment?
3 When should people with epilepsy be referred for a neuropsychological assessment?
4 What should be expected from a neuropsychological assessment?

The following recommendations have been written to be broad enough to assist health care clinicians in established epilepsy centers and community settings, as well as those who are involved in setting up new services. It is explicitly recognized that these recommendations may be difficult (if not impossible) to implement in certain low- and middle-income settings where specialist training is not available and there are large treatment gaps for basic health care interventions. In these settings, these recommendations should be viewed as aspirational and a resource for lobbying local health organizations to expand training and access for neuropsychological services.

## Methods

The recommendations build on the work of the former ILAE Neuropsychology Task Force (2009–2013) that comprehensively examined models of neuropsychological care in people with epilepsy, and undertook a formal process of ranking a large set of specific recommendations for advancing clinical care in epilepsy generated by >50 epilepsy specialists from 13 countries with expertise relevant to adult and pediatric neuropsychology.[1] In addition, a detailed survey of neuropsychological assessment practices in epilepsy was conducted across 17 countries to identify common practices in the field.[2] The results endorsed assessment of a core set of cognitive and psychological domains in people with epilepsy that are reflected directly in the current recommendations.[2,3] The recommendations are also informed by the latest research findings, and the outcome of detailed discussions between specialist epilepsy neuropsychologists from around the world serving on the current ILAE Neuropsychology Task Force (2013–2017), with the aim of providing a representative, consensus view.

The recommendations are focused broadly on the role of neuropsychological assessment in the routine care of children and adults with epilepsy across a diversity of health care settings. The long-standing role that neuropsychology has played in the diagnostic work-up of patients admitted for surgical characterization and associated specialized topics[4] will be addressed in the second report in this series.

## What Is the Role of a Neuropsychological Assessment?

The role of a neuropsychological assessment in the routine care of people with epilepsy is to provide a comprehensive and objective assessment of an individual's cognitive and psychological functioning. This is typically for the purpose of addressing a referral question, taking account of the patient's medical history and broader psychosocial functioning. At times this role may be diagnostic, given that impairments in cognition or behavior can provide clues to the lateralization or localization of the seizure network, or the nature of the epilepsy syndrome. It may also involve differentiating the neurological, psychological, and social processes affecting a patient's clinical presentation at a given point in time, to inform clinical decision making and the provision of optimal treatment. At other times the role may be prognostic, with assessments used to monitor and estimate the effect of ongoing seizures or a particular treatment on the future cognitive and behavioral functioning of an individual. Moreover, the role typically involves psychoeducation of patients and families about the nature and implications of the assessment results, addressing the impact of epilepsy on the patient and family, management of cognitive or behavioral comorbidities, and any educational, vocational, or psychosocial difficulties. It may also extend to the provision of psychological, cognitive, or behavioral treatments to assist patients with cognitive and psychosocial functioning in day-to-day life.

Given these many and varied roles, it goes without saying that neuropsychological assessment in epilepsy involves more than just the administration, scoring, and interpretation of tests. It requires the training and background to synthesize information from the tests, combined with a carefully taken biopsychosocial history, other neurodiagnostic test results, and behavioral observations to communicate the results and their implications effectively to patients, families, and clinicians. Needless to say, this cannot be achieved through only the use of screening or computerized assessment batteries, or evaluations based primarily on patient self-report. Although these procedures provide useful ways of identifying individuals who may require more detailed neuropsychological assessment, they should be considered adjunct procedures rather than a substitute for neuropsychological assessment. At the core of neuropsychological assessment in people with epilepsy is an understanding that epilepsy arises from a disease of brain networks that support normal developmental and aging processes through complex and dynamically changing cognitive and behavioral functions,[5] the assessment of which lies at the interface of mind, brain, and behavior.

## Who Should Do a Neuropsychological Assessment?

### Trained personnel

Neuropsychological assessments should be conducted only by individuals who have undergone specialist training in clinical neuropsychology. This may involve the assistance of a psychometrician working under the supervision of a clinical neuropsychologist. In some parts of the world, training is in addition to basic training as a clinical psychologist, whereas in other regions, neuropsychologists train separately. Neuropsychological training requires detailed knowledge of brain-cognition-behavior relationships, based on rigorous training in brain anatomy and function as well as cognitive processes of the human mind and their disorders. It also requires a comprehensive understanding of the psychometric properties of standardized cognitive and behavioral assessments, and their skilled delivery and clinical interpretation. This specialist training, combined with the experience of working with general neurological or psychiatric populations, forms the bedrock of core competencies within the profession. Additional epilepsy-specific training is then required to develop expertise in assessing the relative contributions of neurological, cognitive, psychosocial, and cultural factors to the neuropsychological profiles of people with epilepsy[6] (Fig. 1). In some, but not all parts of the world, epilepsy-specific training is associated with formal credentials and boarding procedures. Furthermore, for those working with children, training in developmental psychology and developmental neuropsychology is essential, because brain–behavior relationships differ between adults and children.

## When Should People with Epilepsy Be Referred for an Assessment?

### At epilepsy onset for routine screening of cognitive or behavioral difficulties

In children and adults, cognitive or behavioral difficulties may already be present at seizure onset, with a clinical history of problems or complaints preceding diagnosis. Research has clearly shown that approximately half of newly diagnosed children or adults with epilepsy have demonstrable cognitive or behavioral difficulties on testing.[7–9] Thus, we recommend at a minimum routine screening for cognitive and behavioral difficulties in all children and adults newly diagnosed with epilepsy, accompanied by the provision of advice on the risks of cognitive and behavioral difficulties associated with the condition. As noted, routine screening provides an efficient and relatively inexpensive method for identifying people who require a more detailed (and expensive) neuropsychological assessment. Given the insidious evolution of some epilepsies, it can also provide a minimal baseline from which to measure the cognitive course of the disease, or the effects of subsequent treatment. In addition to computerized assessment batteries or self-report questionnaires, screening may involve clinician questioning of the patient's subjective cognitive complaints, such as attention, memory, or word-finding difficulties. Psychological adjustment problems or mood disorder may also be present at diagnosis, for which the patient and family may benefit from psychoeducation or psychological treatment.[10] The benefits of brief or targeted interventions at onset may extend to longer-term medical outcomes, as mood and adjustment difficulties at the time of diagnosis have been shown to predict seizure recurrence.[11]

### When there are signs or symptoms of a focal cognitive impairment

When cognitive deficits are suspected, a neuropsychological assessment provides an objective measure of the extent to which these deficits are global or more focal and limited to particular domains. The primary purpose of the assessment can be to gauge a person's current cognitive functioning without consideration of etiologic factors. Alternatively, focal symptoms or signs of memory difficulties or other cognitive problems can be used to provide critical diagnostic information about the syndrome, lesion location, or seizure network underpinning the patient's epilepsy. The assessment may also be used to identify the presence of atypical cognitive organization for particular functions (i.e., reversed language dominance), or to differentiate ictal from interictal cognitive and behavioral effects.

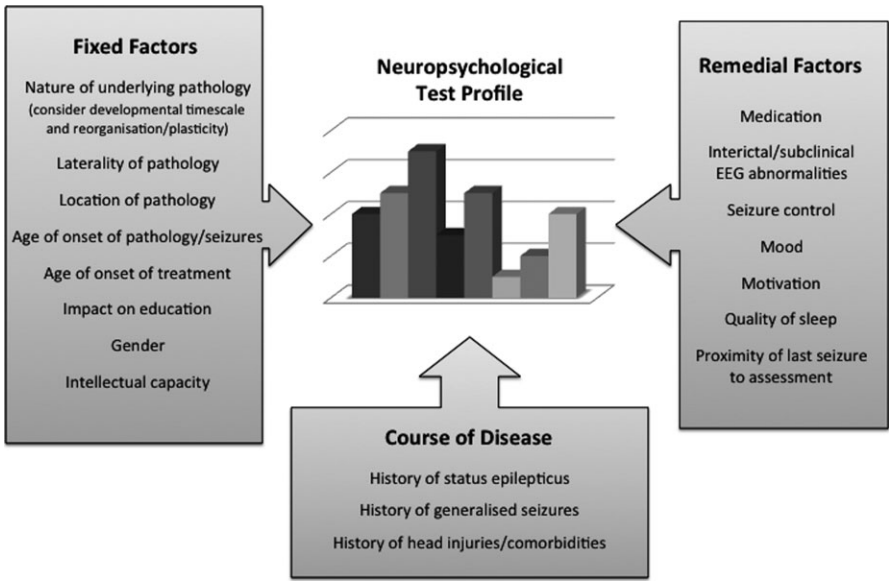


**Figure 1.**
Factors influencing performance on neuropsychological tests in epilepsy (from Baxendale and Thompson[6]). *Epilepsia* © ILAE

In adults with well-controlled epilepsy, memory difficulties are often the only daily manifestation of their condition, and their subjective complaints may be frequent. These complaints may reflect psychological (depression or anxiety) or neurocognitive mechanisms depending on the location of the epileptogenic focus. Neuropsychological assessment may help differentiate between these two explanations and inform treatment decisions.[12] Moreover, although subjective memory difficulties may be the presenting complaint, oftentimes the fundamental cognitive problem may lie in other areas. For example, word-finding difficulties may give rise to a subjective memory complaint that indicates pathology in the language network rather than the memory system per se.

In the absence of patient subjective complaints, family reports of difficulties with particular functions like memory, attention, or disorganization in daily life may trigger the need for an assessment, particularly in people with frontal lobe dysfunction who lack insight into their difficulties. Screening or formal assessment may also be indicated in patients with epilepsies that have been traditionally considered cognitively "benign," such as the genetic generalized epilepsies and other syndromes.[13–15] Alternatively, memory or other cognitive difficulties may become apparent on assessment, providing an independent and objective basis for educating the patient and others about the neurologic basis of the problem and justifying a referral for intervention. Early referral and intervention is particularly pertinent in cases where difficulties may be reversible.

In children, attention and memory difficulties may be reported by family members and/or school staff and may also be apparent on clinical examination. Memory deficits are more likely to be apparent in adolescents than in younger children.[16,17] Even in children with focal epilepsy, cognitive impairments may be diffuse and affect multiple domains, with similarities in impairments noted between many epilepsy syndromes.[18] Thus, it is important to ask about cognitive deficits, and not rely on the idea of syndrome-specific disorders. Because of developmental changes, the child's pattern of cognitive strengths and weaknesses may also change over time. Likewise, as the complexity of academic demands increases in higher grade levels, children who did well in school in earlier years may begin to struggle. For these reasons, repeat assessments over time may be warranted to provide the necessary supports for children and their families.

### When there is a question of neurodevelopmental delay, behavioral or learning difficulties, or cognitive decline

In children with epilepsy, developmental delay may be obvious. In this case, longitudinal neuropsychological assessments can be used to quantify and track a child's progress across multiple domains (cognitive, behavioral, emotional, and social) and ensure that appropriate educational, family, and social supports are in place. In others with apparently normal development, problems at home or recent onset of learning difficulties at school may point to underlying cognitive decline, with a slowed rate of cognitive development and gradual falling behind, or a premature plateau in development.[17,19] Here again, neuropsychological assessment can be used to characterize and quantify any difficulties and monitor development over time so that available treatments or supports may be implemented.

In adults, problems with work, memory, or adaptive skills may have an insidious onset, only gradually coming to the attention of the patient or family. Although the rate of normal age-related decline in cognitive function is similar in people with epilepsy to that in the healthy population, many start from a lower base and so develop disabling cognitive

or behavioral problems earlier in life.[17] Repeated head injuries, episodes of status, and atypical seizure clusters may also precipitate or exacerbate cognitive decline.[20–22] In these cases, serial neuropsychological assessments again ensure that any decline is carefully documented, and provide backing for initiating appropriate treatment, and vocational and community supports.

### When evaluating the effects of the disorder and its treatment

Serial neuropsychological assessments provide an invaluable tool for guiding and evaluating treatment effects, detecting clinically meaningful changes in cognition or behavior associated with medication changes, or following neurosurgery in adult and paediatric populations. For instance, in drug-naive patients with new-onset epilepsy, a baseline neuropsychological assessment forms the platform from which to reliably detect drug effects on repeat assessments.[23] The assessment may also be valuable in detecting noncompliance with treatment regimens, revealing the presence of a deficit in memory, language, or executive function that prevents a patient from being able to follow the schedule of medication dosing prescribed by the physician. In this case, the findings indicate that noncompliance is not a matter of will or motivation but rather an inherent limitation in the person's ability to comprehend or follow instructions. Accelerated forgetting may also be evident in some patients, who perform well on standard neuropsychological assessment, but display rapid loss of newly learned information over the following days or weeks. Accelerated forgetting is a common, persistent memory complaint after transient epileptic amnesia (TEA), and may be best detected by repeat assessments targeting anterograde memory function over a short time interval.[24]

### When not to refer

Other than in certain circumstances, people are not routinely referred for a repeat neuropsychological assessment within 6–9 months of a previous assessment. Practice effects can obscure deterioration on tests that would otherwise be sensitive to pathologic decline. This is particularly true for measures of attention, memory, speed of information processing, and higher-level executive functions.[25] Exceptions to this rule include when someone has experienced an episode of status epilepticus or other major event or illness that may have resulted in a significant stepwise deterioration of function.

Neuropsychological assessment may also be impractical and add limited information in the setting of an acute insult or illness that is expected to recover over a short period. This includes assessment of patients during the postictal phase, where diffuse cerebral dysfunction produced by a seizure provides limited diagnostic information. Rather, the level of impairment and evolution of recovery in the acute setting may be evaluated more efficiently by brief bedside examination of basic cognitive functions.[26] This type of assessment can also be useful when evaluating a patient's ability to provide informed consent in the acute setting.

## What Can Be Expected from an Assessment?

### Reliable and valid test results

Because this report focuses on the importance of neuropsychological assessment for addressing core clinical questions in people with epilepsy, we are not going to recommend specific cognitive tests or neuropsychological assessment batteries. Test batteries have been previously recommended,[3,27] but are subject to regional variations and need to take cultural and linguistic factors into account.[28] Herein, we recommend that at a minimum a neuropsychological assessment covers a core set of cognitive domains that are universal (Table 1). These domains should be tested using standardized measures with robust psychometric properties, and culturally specific, up-to-date norms. In some countries, standard tests of effort are also routinely used to ensure reliability of assessment results. For serial assessments, reliable change indices or standardized regression-based measures should be used to assess change over time.[30] Although a core battery of tests can be valuable, an increasingly common approach is to use a flexible battery with additional tests tailored to the clinical referral question and the individual needs of the patient. This allows careful assessment of the functioning of specific domains, based on hypotheses generated from clinical interview, observation of the patient, and review of medical records. Such flexibility is especially important for the approach to assessment with children, as tests need to be age-sensitive and appropriate for the child's developmental level.

It should be noted that most neuropsychological tests and their normative databases have been developed in upper-income settings. Although there is a clear need to adapt them to other low- and middle-income settings, this needs to proceed carefully and deliberately. Test item content may be highly culture-bound. Some people in these settings may have limited experience in school and thus may be less familiar with the goals and processes of assessment. Whenever possible, validation studies should be carried out in local populations and local norms developed to ensure that test format, content, and administration are culturally appropriate. Also relevant is the emerging global issue of an aging world population and the need for validation studies in elderly patients with epilepsy. Given the increased risk of both epilepsy and neurocognitive disorders with advancing age, we recommend routine neuropsychological assessment in elderly patients, particularly in those with new-onset epilepsy.[31]

**Table 1. Core cognitive and psychological domains**

| | |
|---|---|
| Cognitive domains | |
| General intellect | Estimated premorbid intellect |
| | Current intellectual function |
| Attention and speed of processing | Sustained, selective, and divided attention |
| | Psychomotor speed |
| Memory | Learning, short- and long-term free recall, recognition |
| | Autobiographic, prospective, and semantic memory |
| | Different types of verbal and nonverbal material |
| Language | Language comprehension, verbal expression, naming, repetition, and speech production |
| Spatial functions | Visuoperceptual and visuoconstructional abilities |
| Executive functions | Working memory, idea generation (fluency), verbal and nonverbal reasoning, cognitive flexibility (switching), planning and execution, response inhibition, and social cognition[a] |
| Sensory and motor functions | Sensory-motor perception and response, manual dexterity and strength, and praxis |
| Academic skills | Reading, writing, spelling, and numeracy |
| Psychological domains | |
| Personality | Dimensional personality traits |
| Mood | Depression, anxiety |
| Behavior | Illness beliefs and coping strategies |
| | Quality of life and daily psychosocial functioning |
| | Screening of other psychiatric disorders and behavioral comorbidities |

[a]Although not routinely tested, social cognition is being increasingly recognized as relevant to the assessment of people with epilepsy and includes processes such as understanding and managing emotions in a social context and theory of mind.[29]

## Psychological assessment

It is important not to forget the "psychological" in a neuropsychological assessment. This involves evaluating the effect that epilepsy is having on the individual and the family, including patient and family beliefs about the disorder, its perceived stigma, and available coping resources. Typically, this assessment will cover a range of psychosocial domains, including the patient's mood and psychological functioning, as well as physical, educational/vocational, family, and social functioning (Table 1). Either a qualitative and/or quantitative approach can be used. Quantitative metrics derived from measures of health-related quality of life, such as the minimum clinically important difference (MCID), assess the impact of epilepsy across these domains, including the extent of any change following treatment.[32] Dimensional measures of personality and mood and behavioral symptom checklists can provide additional information about psychopathology and behavioral comorbidities, including potential risk and protective factors relevant to individual patients. Given the high comorbidity of depression and anxiety in epilepsy, risk for depression and its complications (such as suicide) should be screened for routinely.[33,34] Such information is vital to disentangling the neurologic, psychological, and social factors contributing to a patient's clinical presentation, and in some instances, may lead to a recommendation for formal psychiatric evaluation as an outcome of the neuropsychological assessment.

## Qualitative assessment

Qualitative approaches, such as clinical interview and careful observation of a patient's presentation and behavior, form an integral part of the neuropsychological assessment, informing case formulation and clinical recommendations. At the very least, a neuropsychological assessment should include a detailed history of cognitive and behavioral complaints, and an account of their subjective impact on everyday function. Careful characterization and delineation of ictally related as compared to interictal changes in cognition and behavior are imperative for providing an accurate neuropsychological assessment. Likewise, a clear history of the timing of cognitive or behavioral changes relative to seizure frequency and specific treatment interventions can be fundamental to guiding clinical decision making and future treatments. For patients presenting acutely, or otherwise not amenable to psychometric testing, a qualitative assessment or bedside neurobehavioral examination may provide the only viable means of directly evaluating the patient's current cognitive and psychological status. Observer-based measures or detailed clinical interview with carers and/or family members provide other important perspectives. In the latter case, it is worth keeping in mind that family aggregation of cognitive or psychiatric issues may be pertinent to the attribution of difficulties observed in the patient.

## Case formulation

A neuropsychological assessment should provide the referring clinician with an objective profile of cognitive function across multiple cognitive domains. This should include a clear description of the cognitive strengths and weaknesses of the patient relative to estimated premorbid levels of functioning. The case formulation should also address the patient's emotional and psychosocial profile, and identify factors likely contributing to any deficits identified on qualitative and quantitative examination. From mood to medication, these factors are heterogeneous and can be fixed or fluctuating, irreversible or remediable (Fig. 1), informing clinical decisions relating to diagnosis, prognosis, and treatment.

## Feedback and clinical recommendations

A neuropsychological assessment should also provide clear advice about the clinical implications of the assessment results, including the need for any future reviews or other investigations and when these might best occur. Providing feedback to patients and families forms a key part of the assessment process and can have direct therapeutic benefits, enhancing cognitive and emotional well-being.[35]

Feedback typically includes psychoeducation about the nature of perceived cognitive difficulties, their basis and relationship to the epilepsy, as well as any other psychological factors that are relevant. Specific clinical recommendations should be made about what (if anything) can be done to improve a patient's cognitive or psychosocial functioning to alleviate the distress of any difficulties identified. Evidence for neuroplasticity in the pediatric and adult brain underpins an expanding literature on neurorehabilitation and the use of cognitive retraining to assist patients with memory or other cognitive deficits after brain injury.[36] Although epilepsy research in this area is still in its infancy, a number of studies have demonstrated effective cognitive rehabilitation strategies for impairments of attention and memory in patients with epilepsy.[37–39] These strategies include cognitive retraining paradigms and compensatory strategies to circumvent difficulties in daily life, which can be recommended alongside of educational, vocational, or community supports to assist patient and family psychosocial functioning.[40] Where relevant, psychological treatments such as cognitive behavior therapy or anxiety management can also be recommended to assist patient and family adjustment to epilepsy, complementing medical therapies.[41–43]

## Conclusions

Neuropsychological assessment is a noninvasive and minimally resource intensive investigation in people with epilepsy. There has been a long and productive relationship between neuropsychology and epilepsy, perhaps more so than with any other condition. While this relationship has grown from the specific area of epilepsy surgery, it now extends far beyond this. Given its breadth and depth of scope, neuropsychological assessment remains a pivotal investigation in the routine care of people with epilepsy that provides unique information about brain functioning, even in our current age of neuroimaging. Its strength lies in its consideration of the whole person embedded within a broader social and cultural context, bringing together complex, interacting processes of mind, brain, and behavior that directly inform diagnosis, prognosis, and treatment. Considered in this light, the current challenges associated with treating epilepsy and its often broad psychosocial effects call for increased use of neuropsychological services across international epilepsy settings to complement the range of other diagnostic and treatment modalities required to improve the care of people with epilepsy in the 21st century.

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## Disclosure

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