

HOME/FAMILY SCREENING FOR COGNITIVE CHANGES: QUICK GUIDE

Some things you can do to obtain 'personal best' behavior and function information in advance of when you might suspect that dementia may be present



National Task Group
on Intellectual Disabilities
and Dementia Practices

www.the-ntg.org

What is screening and assessment? **Screening** is used to identify the possible presence of an as-yet-undiagnosed condition in individuals who are showing no signs or symptoms. **Assessment** is an evaluation of a person that includes a health and social history, physical examination, lab work, and other tests when some condition is suspected. It is the next step in the process to reach a diagnosis. **Diagnosis** is the identification of a condition or illness.

What is 'personal best'? Ahead of a time when you might expect to see changes in an adult with an intellectual disability, it is highly beneficial to obtain and record how the person functions and can do things at their best. This 'baseline screening' will help in the future when a clinician is asked to assess the adult. To obtain this information, you can do an informal or formal screening.

How do I do an 'informal' screening? Collecting 'personal best' information can involve some simple things, like taking pictures of the adult doing things to help around the house, working on a hobby, or enjoying events – and creating a diary of what specifically they were doing and how well they did it. Another way is to *use your smartphone* and record the adult doing some specific things, like walking back and forth, carrying on a conversation, and answering some easy questions (such as 'what is today', 'what is your address', 'what did you do yesterday'...), and completing simple tasks (such as unlocking and locking a small padlock, and picking up some coins and putting them in a small jar). All these things help pick up on specific verbal and physical

functional skills that are useful to know about when later a clinician may be asked to do an assessment.

How do I do a 'formal screening'? You can use a formal screening instrument, such as the National Task Group Early Detection Screen for Dementia. This was created as a formal administrative screen for early-stage dementia in adults with an intellectual disability. Using the NTG-EDSD, you will be able to collect information on conditions present, whether medical or behavioral, the person's typical performance on common tasks, medications prescribed, and whether behaviors are new or long-standing. Such screenings should be done in their 50s for most adults (or in their 40s, if the adult has Down syndrome).

What do I do with this information? Sharing a thorough history of changes, especially those which show a gradual, yet progressive decline in function or behavior, with your healthcare provider could be an important key to a diagnosis. If there is no urgency, simply store the recordings and notes for future use. If you use the NTG-EDSD, you can bring this with you when the adult next has a health/wellness visit with their healthcare provider.

Where can I get help with these screenings? More information is available at www.the-ntg.org/ntg-edsd.

The mission of the NTG is to advocate for services and supports for people with intellectual disability and their families who are affected by Alzheimer's disease and dementias.

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Doing an informal screening

Creating your loved one's life story will be extremely helpful when you begin seeing changes that are of concern. Those old photos that may be in a shoe box in the closet will help you put together a story of who your loved one is and has been. Through a life story others will know about the skills and interests your family member has had throughout their life. Sort through your photos and put them in a scrap book. Make notes next to each photo to identify when it was taken and explain what the person is doing.

If you have a smartphone, an easy way to gather information is to use the phone's video function to record some of the things your relative can typically do. Save this video and keep it in a safe place. Then you can share it with your healthcare provider should you have suspicions about changing behavior. To create a *baseline file*, the NTG recommends recording several things your relative can do. These would include:



Walking back and forth, carrying on a conversation, and answering some easy questions (such as what is today, what is your address, what did you do yesterday, etc. ...), and completing simple tasks (such as unlocking and locking a small padlock, and picking up some coins and putting them in a small jar).

Doing a formal screening

The NTG's Early Detection and Screening for Dementia instrument can be helpful to starting that critical conversation with healthcare providers as your suspicions about some notable changes in behavior and function that are occurring, and which may warrant further medical review. The NTG-EDSD is a 6-page form that permits a family member/s to note significant aspects of an adult's behavior and functioning.

A thumbnail image of the NTG-EDSD form, showing the title 'NTG-EDSD' and various sections for data entry.

You can download a copy of the NTG-EDSD at <https://www.the-ntg.org/ntg-edsd>. Besides English, the form is available in 10 other languages. The form asks you to note information about the adult, much of which you may have from their health record, your familiarity over time, or from your recent observations. Using the NTG-EDSD will give you a place to record your impressions and make note of any concerns you have.

What you note on the screening form can be very helpful to your healthcare provider or staff – to begin that conversation about your concerns. If your healthcare provider is not be familiar with the NTG-EDSD, the NTG has a ***Physician's Quick Guide For Using The NTG-EDSD***, which can be obtained at [8c1d0a_ddeaed76f098462191e2dea25f3ef50d.pdf](https://www.the-ntg.org/8c1d0a_ddeaed76f098462191e2dea25f3ef50d.pdf) ([the-ntg.org](https://www.the-ntg.org)).

For instructions about undertaking an informal screening, see the *Dalton Protocol for Recording Baseline Information*, which is available at <https://www.the-ntg.org/undertaking-assessments>. For some of the information on informal screening, we credit the *Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders* (2017), which is available at <https://www.the-ntg.org/ntg-technical-assistance>.