

# 2024 Evaluating Dementia Services and Supports: Instrument Resource List

## *4th Edition*





# 2024 Evaluating Dementia Services and Supports: Instrument Resource List *4th Edition*

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# Introduction

Dementia service providers—such as Administration for Community Living (ACL)-funded Alzheimer’s Disease Programs Initiative (ADPI) grantees—evaluate their programs and services to support their own internal planning and to demonstrate program impact to funders. This resource list is intended to help service providers identify evaluation instruments that are appropriate for community-based dementia services and relatively easy to access. Choosing existing, thoughtfully developed instruments saves time and lends credibility to evaluation findings. The list does not represent an endorsement of any specific instrument.

ADPI grantees are required to measure the impact of direct service activities. This list includes instruments that measure program outcomes such as enhanced quality of life or increased knowledge of dementia. Other instruments on the list are primarily intended to assess participants’ condition or needs—for example, cognitive screening tools or functional abilities related to activities of daily living. Some instruments can be used as both an assessment tool and an outcome measure. Program managers and evaluators should consider the intended impact of their programs and services to ensure that they select instruments that will demonstrate the impact of the services provided.

Instruments are sometimes designed for a specific audience. We recommend reviewing instrument content and administration instructions carefully to ensure that they are appropriate for the intended audience(s) and outcome(s). The resource list references validation studies where relevant, which may also provide implementation guidance. Note that some instruments were developed for dementia services, whereas others are not dementia specific.

## Development of the Resource List

We identified instruments through several sources, including current and past ADPI grant project plans and reports; a literature search; and Alzheimer’s, aging, health care, and research websites.

The following criteria were used in selecting instruments:

1. Appropriate to community services
  - Only instruments relevant to the community setting were included.
  - Most instruments are brief and do not require extensive staff training or clinical expertise.

## Introduction

2. Available
  - All instruments on this list are available at low or no cost; most may be accessed online.
3. Valid
  - Most instruments on this list have been validated through research; citations are provided in the References section. A few instruments have not been validated but were developed by experts in the field.
4. Strengths-based
  - Historically, many evaluation instruments for dementia services have assumed a negative caregiving experience and sometimes a negative view of people living with dementia or the symptoms of dementia. ACL emphasizes a strengths-based approach to evaluation that recognizes an individual's existing strengths and coping abilities. Instruments selected for this resource list are person centered and use primarily neutral language.

## How to Use This Document

Instruments are categorized by domain, and domains are separated into individual tables, which are arranged alphabetically beginning on page 5. Within each domain, instruments are listed alphabetically by name.

Where appropriate, instruments are listed within more than one domain. For example, if an instrument includes items related to both Self-Efficacy and Dementia Knowledge and Skills, it is listed in both tables.

## Obtaining Permission to Use Instruments

Some instruments are in the public domain and may be used freely without modification and with attribution to the original developer. In other cases, permission is required to use an instrument, the developer must be notified, proper citation must be used, and/or the instrument must be used in its entirety without changes. Follow the guidance provided in the "Permissions" column of the instruments tables. Please note that use of individual items from an instrument may require specific permission from the developer, even if not noted in the tables below.

Most instruments can be accessed online (the name of the instrument is linked to the online source), by contacting the developer (an email address is provided), or through the original research article (which may require a nominal fee). Select instruments are



available through the [National Alzheimer's and Dementia Resource Center \(NADRC\) website](#) with permission from the developer(s); permission instructions within the tables below must be followed.

## Translation into Other Languages

Many instruments included in the resource list have been translated and validated in other languages. It is beyond the scope of this list to provide full information on translations, but the Notes column indicates cases where translated versions are available through a central website. We recommend searching online for existing validation studies of translated versions before creating your own translation; some instruments may also require developer permission to translate.

## Legend

### *Domain*

Tables are categorized by domain, which indicates the topic that the instrument is intended to measure. Some instruments are listed under more than one domain; these may include subscales of two or more domains.

### *Instrument*

The name of the instrument is linked to a copy of the instrument where available. If more than one version of the instrument is available, this is indicated.

The name of the developer(s) or researcher(s) is linked to the complete research citation in the References section. Proper citation is required to use some instruments.

### *Number of items*

This column indicates the number of questions or statements on the instrument as a measure of the instrument's length. In some cases, a question may have more than one part.

### *Sample item(s)*

These are examples of actual questions or statements, intended to give a sense of the tone and focus of each instrument.

## **Introduction**

### ***Instructions***

If available, the instructions indicate where to find information on administration, scoring, and interpreting results.

### ***Permissions***

This column indicates what permission is required to use the instrument, and if applicable, whom to contact for permission.




### ***Notes***

Where available, the notes provide information on translations, associated fees, or other information about obtaining or using the instrument.





## **Evaluation Instrument Tables**

Following are tables of instruments, categorized by domain and arranged alphabetically. Within each table, instruments are listed alphabetically by name.




**Table 1. Activities of Daily Living and Instrumental Activities of Daily Living**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Care Needs Assessment Tool</a>  (Alzheimer's Los Angeles)	23	Has it happened in the last month; how much does it bother the caregiver: <ul style="list-style-type: none"> <li>Resists bathing or showering</li> <li>Difficulty with dressing and grooming (brushing hair/teeth, shaving, etc.)</li> </ul>	Administration and scoring instructions are included on the instrument.	Use the following citation. No other permissions are required. Materials reproduced/adapted with permission from Alzheimer's Los Angeles. © 2016 Alzheimer's Los Angeles	
<a href="#">Functional Activities Questionnaire</a>  (FAQ)  (Pfeffer et al.)	10	Rate the patient's ability: <ul style="list-style-type: none"> <li>Writing checks, paying bills, balancing checkbook</li> <li>Preparing a balanced meal</li> </ul>	Administration and scoring instructions are included on the instrument.	Contact Robert Pfeffer at <a href="mailto:RobertI.Pfeffer@nyu.mc.org">RobertI.Pfeffer@nyu.mc.org</a> for permission. A nominal fee may be required to use the instrument.	

**Table 2. Behavioral Symptoms**






Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Care Needs Assessment Tool</a>  (Alzheimer's Los Angeles)	23	<ul style="list-style-type: none"> <li>• Repetition (doing or saying things over and over)</li> <li>• Sundowning (more confusion/restlessness in late afternoon/evening)</li> <li>• Suspiciousness/paranoia (accusing/blaming)</li> </ul>	Administration and scoring instructions are included on the instrument.	Use the following citation. No other permissions are required. Materials reproduced/adapted with permission from Alzheimer's Los Angeles. © 2016 Alzheimer's Los Angeles	
<a href="#">Neuropsychiatric Inventory (NPI)</a>  (Cummings)	12	<p>Caregiver answers questions about behavioral symptoms, frequency, severity, and how much distress the symptoms cause:</p> <p>Example: Apathy/indifference</p> <ul style="list-style-type: none"> <li>• Has the patient lost interest in friends and family members?</li> <li>• Is the patient less enthusiastic about his/her usual interests?</li> </ul>	Administration and scoring instructions are available on the instrument.	<a href="#">Conditions</a>  of use are provided by <a href="#">Mapi Research Trust</a> . 	

**Table 3. Caregiving Experience**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Burden Scale for Family Caregivers (BSFC)</a>  (Graessel et al.)	28	<ul style="list-style-type: none"> <li>I often feel physically exhausted.</li> <li>I have enough time for my own needs and interests.</li> <li>The care I give is acknowledged by others.</li> </ul>	Scoring and interpretation instructions are included on the instrument.	Contact Elmar Graessel at <a href="mailto:elmar.graessel@uk-erlangen.de">elmar.graessel@uk-erlangen.de</a> .	<a href="#">Translations are available.</a> 
<a href="#">Caregiver Grief Scale</a> (Meichsner, Schinköthe, & Wilz)	11	<ul style="list-style-type: none"> <li>I miss so many of the activities we used to share.</li> <li>I feel that life is empty without her/him.</li> </ul>	Scoring instructions are included on the instrument.	This scale may be used for nonprofit purposes. Credit the developers by using the citation provided. For other uses, contact Franziska Lechner-Meichsner at <a href="mailto:meichsner@psych.uni-frankfurt.de">meichsner@psych.uni-frankfurt.de</a> and Gabriele Wilz at <a href="mailto:gabriele.wilz@uni-jena.de">gabriele.wilz@uni-jena.de</a> .	
<a href="#">Caregiver Outcomes of Psychotherapy Evaluation (COPE)</a>  (Aguirre et al.)	8	<ul style="list-style-type: none"> <li>I am confident in my caregiving skills.</li> <li>I feel able to manage my emotional well-being.</li> <li>I am confident in facing challenges ahead.</li> </ul>	Scoring instructions are included with the research article.	Please notify Alyssa Aguirre of use at <a href="mailto:alyssa.aguirre@austin.utexas.edu">alyssa.aguirre@austin.utexas.edu</a> and use the citation provided. No other permissions are required.	






(continued)

**Table 3. Caregiving Experience (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Caregiver Self-Assessment Questionnaire</a>  (Epstein-Lubow et al.)	18	<ul style="list-style-type: none"> <li>During the past week or so, I have felt useful and needed.</li> <li>During the past week or so, I have felt lonely.</li> <li>Please rate your current health compared to what it was this time last year.</li> </ul>	Scoring and interpretation instructions are included on the instrument.	Contact <a href="mailto:info@healthinaging.org">info@healthinaging.org</a> for permission.	Translations are available through the website.
<a href="#">Dementia Carer Assessment of support Needs Tool (DeCANT)</a>  (Clemmensen et al.)	25	Do you have a need for support: <ul style="list-style-type: none"> <li>to manage stress?</li> <li>to feel confident in the caring role?</li> <li>to maintain your social network?</li> </ul>	<a href="#">Scoring instructions</a> are included in the manual.	DeCANT may not be modified but may be used free of charge for clinical and scientific purposes according to the specifications outlined in the manual.	Users who wish to translate the scale or adapt it culturally should contact Trine Holt Clemmensen at <a href="mailto:thcl@ucl.dk">thcl@ucl.dk</a> .
<a href="#">Kingston Caregiver Stress Scale (KCSS)</a>  (Sadak et al.)	10	<ul style="list-style-type: none"> <li>Has there been a change in your relationship with your spouse/relative?</li> <li>Are you having any conflicts with your previous daily commitments (work/volunteering)?</li> </ul> Do you have concerns regarding the future care needs of your spouse/relative?	<a href="#">An administration and scoring manual is available.</a> 	No special permissions are required.	The instrument is available in <a href="#">several languages.</a> 




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**Table 3. Caregiving Experience (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Perceived Change Index</a> ( <a href="#">Gitlin et al.</a> )	13	Caregiver indicates whether the item has become worse, stayed the same, or improved in the past month: <ul style="list-style-type: none"> <li>Your feelings of being calm or relaxed</li> <li>Your ability to handle new caregiving problems</li> <li>Your ability to have time for yourself</li> </ul>	Scoring instructions are available from the NADRC.	Notify Laura Gitlin at <a href="mailto:lng45@drexel.edu">lng45@drexel.edu</a> of use. No other permissions are required.	
<a href="#">Perceived Stress Scale (PSS)</a>  ( <a href="#">Cohen, Kamarck, &amp; Mermelstein</a> )	4-, 10-, and 14-item versions	In the last month, how often have you: <ul style="list-style-type: none"> <li>Felt that you were unable to control the important things in your life?</li> <li>Felt that things were going your way?</li> </ul>	<a href="#">Scoring instructions are available.</a> 	Physicians, clinical practices, and unfunded academic users may obtain the instrument at no cost. Additional permissions information is available from <a href="#">Mapi Research Trust.</a> 	Translations and additional information are available through the <a href="#">PSS website.</a> 
<a href="#">Positive Aspects of Caregiving</a>  ( <a href="#">Tarlow et al.</a> )	11	Providing help to (care recipient) has <ul style="list-style-type: none"> <li>Made me feel more useful</li> <li>Made me feel needed</li> <li>Enabled me to learn new skills</li> </ul>	Administration instructions are included on the instrument.	Use the citation provided. No other permissions are required.	






(continued)

Table 3. Caregiving Experience (continued)

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Positive Psychology Outcome Measure for Carers (PPOM-C)</a> (Pione et al.)	14	<ul style="list-style-type: none"> <li>I can see positive things in difficult situations.</li> <li>I am able to see the humorous side.</li> <li>I can handle unpleasant feelings.</li> </ul>	Scoring instructions are included on the instrument.	No amendments should be made to item wording or the Likert scale without permission from the measure authors. Please inform Charlotte R. Stoner at <a href="mailto:positivepsychology.dementia@gmail.com">positivepsychology.dementia@gmail.com</a> about how the measure is used, and contact her about amendments or translations.	
<a href="#">Zarit Burden Interview</a>  (Bédard et al.)	12	<ul style="list-style-type: none"> <li>Do you feel strained around your relative?</li> <li>Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?</li> <li>Do you feel that your social life has suffered because you are caring for your relative?</li> </ul>	A user manual with scoring and interpretation instructions is available from <a href="mailto:PROinformation@mapi-trust.org">PROinformation@mapi-trust.org</a> .	Physicians, clinical practices, and unfunded academic users may obtain the instrument at no cost. Additional permissions information is available from <a href="#">Mapi Research Trust</a> . 	Translations are available through the <a href="#">Mapi Research Trust website</a> .   <i>*ADPI grantees should consult with their ACL project officer before proposing this evaluation instrument.*</i>






**Table 4. Cognitive Screening**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Eight-item Informant Interview to Differentiate Aging and Dementia (AD8)</a>  (Galvin et al.)	8	Caregiver indicates changes in the last several years caused by cognitive problems: <ul style="list-style-type: none"> <li>Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)</li> <li>Forgets correct month or year</li> </ul>	Administration and scoring instructions are included with the instrument.	Users must obtain an <a href="#">AD8 license</a> . 	The instrument may be administered over the telephone.
<a href="#">Brief Assessment of Impaired Cognition Questionnaire (BASIC-Q)</a>  (Jørgensen et al.)	10	For person with memory concerns: <ul style="list-style-type: none"> <li>Compared to previously, do you feel that your memory has declined substantially?</li> <li>Do you have more trouble recalling names, finding the right words, or completing sentences?</li> </ul> For informant: <ul style="list-style-type: none"> <li>Compared with a few years ago, how is your spouse/partner/parent/family member at recalling conversations a few days later?</li> </ul>	<a href="#">Administration and scoring instructions are provided in the BASIC-Q manual</a> . 	BASIC-Q may be used without restrictions for clinical and research purposes.	Translations are available by contacting Kasper Jørgensen at <a href="mailto:niels.kasper.joergensen@regionh.dk">niels.kasper.joergensen@regionh.dk</a> .
<a href="#">Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)</a>  (Jorm)	16	Compared with 10 years ago, how is this person at: <ul style="list-style-type: none"> <li>Remembering things about family and friends e.g. occupations, birthdays, addresses</li> <li>Recalling conversations a few days later</li> <li>Remembering where things are usually kept</li> </ul>	Administration instructions are included on the instrument.	Notify Anthony Jorm at <a href="mailto:Anthony.Jorm@anu.edu.au">Anthony.Jorm@anu.edu.au</a> of use. No other permissions are required.	











(continued)

**Table 4. Cognitive Screening (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
Making & Executing Decisions for Safe and Independent Living (MED-SAIL) ( <a href="#">Mills et al.</a> )	12–18 (depending on number of scenarios completed)	Select 2–3 appropriate scenarios. <i>Example:</i> The door to your home is locked and you do not have a key: <ul style="list-style-type: none"> <li>• What would you do if the door to your home was locked and you didn't have a key?</li> <li>• What would you do if [this response] didn't work?</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	The instrument identifies decision-making impairment. Contact Meagan Pitcher at <a href="mailto:Meagan.Pitcher@bcm.edu">Meagan.Pitcher@bcm.edu</a> to obtain access to the instrument.
<a href="#">Memory Impairment Screen by telephone (MIS-t)</a> ( <a href="#">Lipton et al.</a> )	11	<ul style="list-style-type: none"> <li>• Remember 4 words.</li> <li>• Count down from 20 to 1.</li> </ul>	Administration and scoring instructions are included on the instrument.	The instrument is available for academic and clinical use without charge.	
<a href="#">Mini-Cog</a>  ( <a href="#">Borson et al.</a> )	2	<ul style="list-style-type: none"> <li>• Three-word recall</li> <li>• Clock drawing</li> </ul>	<a href="#">Administration instructions</a> and <a href="#">scoring instructions</a>  are available at the links provided.	May not be modified or used for commercial, marketing, or research purposes without permission of the author, Soo Borson, <a href="mailto:soob@uw.edu">soob@uw.edu</a>	Translations are available at through the <a href="#">Mini-Cog website</a> . 

(continued)

**Table 4. Cognitive Screening (continued)**


Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Mini-Kingston Standardized Cognitive Assessment (mini-KSCAR)</a>  (Hopkins & Kilik)	6	Six sub-tests, including: <ul style="list-style-type: none"> <li>• Word recall</li> <li>• Clock test</li> <li>• Abstract thought</li> </ul>	<a href="#">Administration and scoring manual is available.</a> 	No special permissions are required.	<a href="#">The instrument is available in several other languages.</a> 
<a href="#">Montreal Cognitive Assessment (MoCA)</a>  (Nasreddine et al.)	24	<ul style="list-style-type: none"> <li>• Five-word recall</li> <li>• Read list of digits and have the subject repeat them in forward and backward order.</li> <li>• Name as many words as possible in one minute that start with the letter F.</li> </ul>	<a href="#">Training and certification</a>  (1-hour) is mandatory to administer the MoCA.	Permission is required. Information is available on the <a href="#">MoCA website.</a> 	Telephone, paper, digital, and app versions of the MoCA are <a href="#">available at this link.</a> 
<a href="#">Rowland Universal Dementia Assessment Scale (RUDAS)</a>  (Basic et al.)	6	<ul style="list-style-type: none"> <li>• Remembering a list of grocery items</li> <li>• I am going to show you an action/exercise with my hands. I want you to watch me and copy what I do.</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	The instrument is intended to be culturally appropriate across audiences. Scoring information is provided in Chinese and Italian.
<a href="#">Saint Louis University Mental Status Exam (SLUMS)</a>  (Tariq et al.)	11	<ul style="list-style-type: none"> <li>• What day of the week is it?</li> <li>• Please name as many animals as you can in one minute.</li> <li>• You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20. How much did you spend? How much do you have left?</li> </ul>	<a href="#">Instructions and a training video</a>  are available.	No special permissions are required. Contact <a href="mailto:aging@slu.edu">aging@slu.edu</a> with questions.	Translations are available through the website.

**Table 5. Dementia Assessment for People with Intellectual and Developmental Disabilities**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Adaptive Behaviour Dementia Questionnaire (ABDQ)</a> (Prasher, Farooq, & Holder)	15	Dressing: <ul style="list-style-type: none"> <li>Independent, needs no assistance</li> <li>Independent with verbal prompts</li> <li>Minimal assistance (buttons, zippers)</li> <li>Significant hands-on assistance</li> <li>Totally dependent</li> <li>Could never dress self</li> </ul>	Consult the <a href="#">Adaptive Behaviour Dementia Questionnaire instructions</a> .	No special permissions are required.	
<a href="#">Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)</a> (Deb et al.)	56	Is the symptom there, has it always been there, is it new, has it gotten worse: <ul style="list-style-type: none"> <li>Cannot wash and/or bathe without help</li> <li>Withdraws from social activities</li> <li>Needs help eating</li> </ul>	Scoring and interpretation instructions are included on the instrument.	Contact Shoumitro Deb at <a href="mailto:s.deb@bham.ac.uk">s.deb@bham.ac.uk</a> for permission.	
<a href="#">National Task Group on Intellectual Disabilities and Dementia – Early Detection Screen for Dementia (NTG-EDSD)</a> (Silverman et al.)	32	<ul style="list-style-type: none"> <li>Needs help with washing and/or bathing</li> <li>Does not initiate conversation</li> <li>Sleeps during the day more than usual</li> </ul>	Consult the <a href="#">NTG manuals</a> .	No special permissions are required.	Translations are available through the <a href="#">NTG website</a> .

(continued)

**Table 5. Dementia Assessment for People with Intellectual and Developmental Disabilities (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Prudhoe Cognitive Function Test</a>  ( <a href="#">Kay et al.</a> )	21- or 56- item versions	<ul style="list-style-type: none"> <li>• What day of the week is it today?</li> <li>• Touch your ear.</li> <li>• Can you make this? (arrange four matches in a shape of a square)</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	Contact Stephen Tyrer at <a href="mailto:stephen.tyrer@ncl.ac.uk">stephen.tyrer@ncl.ac.uk</a> for more information.
<a href="#">Test for Severe Impairment (TSI)</a> ( <a href="#">Albert &amp; Cohen</a> )	24	<ul style="list-style-type: none"> <li>• Show me how you would use this comb.</li> <li>• Point to your ear.</li> <li>• Which of these is different? [of two paper clips and one pen]</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	

**Table 6. Dementia Attitudes and Stigma**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Brief Tool for Dementia Friendly Educational and Training Sessions (BTDF)</a> (Menne & Guerrero)	7	<ul style="list-style-type: none"> <li>• People with dementia need to feel respected, just like anyone else.</li> <li>• I am motivated to get to know people with dementia better.</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	Versions are available for individual or organizational trainings.
<a href="#">Dementia Attitudes Scale (DAS)</a> (O'Connor & McFadden)	20	<ul style="list-style-type: none"> <li>• I feel uncomfortable being around people with ADRD.</li> <li>• People with ADRD can feel when others are kind to them.</li> <li>• Every person with ADRD has different needs.</li> </ul>	No scoring instructions are provided.	No special permissions are required.	
<a href="#">Dementia Community Attitudes Questionnaire</a> (Read et al.)	10	<ul style="list-style-type: none"> <li>• People with dementia can contribute substantially to their community.</li> <li>• People with dementia have the right to be involved in supported decision making about their future.</li> <li>• I have the potential to improve the lives of people living with dementia.</li> </ul>	Higher scores indicate more positive attitudes. Use of the included demographic questions is optional.	Demographic questions are optional. Otherwise, the questionnaire can only be used in its entirety without changes.	
Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia) (Bhatt et al.)	14	<ul style="list-style-type: none"> <li>• Have you been treated unfairly in your levels of privacy?</li> <li>• Because of your dementia, have some people not taken your opinions seriously?</li> <li>• Have you been treated unfairly by health or medical staff?</li> </ul>	Scoring instructions are included with the scale.	Contact Sara Evans-Lacko at <a href="mailto:S.Evans-Lacko@lse.ac.uk">S.Evans-Lacko@lse.ac.uk</a> for permission. All uses and reproduction should specify a statement of attribution and acknowledgment.	The scale is available in the cited research article.

(continued)

**Table 6. Dementia Attitudes and Stigma (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">General Practitioners' Attitudes and Confidence towards Dementia Survey (GPACS-D)</a> (Mason et al.)	15	<ul style="list-style-type: none"> <li>• Much can be done to improve the quality of life for people with dementia.</li> <li>• The early detection of dementia benefits the patient.</li> <li>• I fear communicating a diagnosis of dementia will damage the doctor patient relationship.</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	Select items may need to be edited for a U.S. audience.
<a href="#">Measures of Stigma and the Social Impact of Disease</a> (Fife & Wright)	24	<ul style="list-style-type: none"> <li>• I feel others avoid me because of my illness.</li> <li>• Some family members have rejected me because of my illness.</li> <li>• I encounter embarrassing situations as a result of my illness.</li> </ul>	No scoring instructions are provided.	Individuals may use this information for research or educational purposes only and not commercial purposes. Use the citation provided. When presenting results using any survey information you obtained from the SABI, please acknowledge the University of North Carolina at Chapel Hill Center for AIDS Research (CFAR), an NIH-funded program (P30 AI50410).	

**Table 7. Dementia Knowledge and Skills**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Basic Knowledge of Alzheimer's Disease Survey (BKAD)</a> (Wiese et al.)	32	<ul style="list-style-type: none"> <li>Poor nutrition may increase AD risk.</li> <li>Trouble counting change may be a sign of AD.</li> <li>AD is a normal part of growing older.</li> </ul>	Scoring instructions are included in the original article.	Please use the citation provided and contact Lisa Wiese at <a href="mailto:lwiese@health.fau.edu">lwiese@health.fau.edu</a> if considering modifications to the scale.	
<a href="#">Brief Tool for Dementia Friendly Educational and Training Sessions (BTDF)</a> (Menne & Guerrero)	7	<ul style="list-style-type: none"> <li>Dementia is part of normal aging.</li> <li>People with dementia may express themselves or communicate through actions instead of words.</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	Versions are available for individual or organizational trainings.
<a href="#">Caregiver Assessment of Behavioral Skill-Self Report (CAB-SR)</a> (Farran et al.)	17	<ul style="list-style-type: none"> <li>If my relative becomes upset, I know how to calm him/her.</li> <li>If my relative accuses me or others of taking or hiding something, I "gently" change the subject.</li> <li>If my relative wanders around during the night, I make sure s/he cannot get out of the house.</li> </ul>	Scoring instructions are included on the instrument.	Permissions are not required for noncommercial use.	

(continued)




**Table 7. Dementia Knowledge and Skills (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Caregiver Communication Competence Scale</a> (Chao et al.)	14	<ul style="list-style-type: none"> <li>Approach patients head-on and establish eye contact; do not abruptly appear beside the patient.</li> <li>Talk to patients in a peaceful, gentle, and friendly manner.</li> <li>Use concise sentences and simple and clear words.</li> </ul>	No instructions are provided.	No special permissions are required.	
<a href="#">Dementia Community Attitudes Questionnaire</a> (Read et al.)	10	<ul style="list-style-type: none"> <li>The main symptom of dementia is always memory loss.</li> <li>Medication is the only treatment that can reduce symptoms related to dementia.</li> <li>People with dementia need assistance all the time.</li> </ul>	Higher scores indicate more positive attitudes. Use of the included demographic questions is optional.	Demographic questions are optional. Otherwise, the questionnaire can only be used in its entirety without changes.	
<a href="#">Dementia Knowledge Assessment Scale (DKAS)</a> (Annear et al.)	25	<ul style="list-style-type: none"> <li>Having high blood pressure increases a person's risk of developing dementia.</li> <li>The sudden onset of cognitive problems is characteristic of common forms of dementia.</li> <li>People experiencing advanced dementia often communicate through body language.</li> </ul>	Scoring instructions are included on the instrument.	Contact Claire Eccleston for permission: <a href="mailto:Claire.Eccleston@uta.edu.au">Claire.Eccleston@uta.edu.au</a> .	

(continued)

**Table 7. Dementia Knowledge and Skills (continued)**











Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Dementia Knowledge Assessment Tool V2 (DKAT v2)</a>  (Toye et al.)	21	<ul style="list-style-type: none"> <li>• Dementia occurs because of changes in the brain.</li> <li>• Brain changes causing dementia are often progressive.</li> <li>• It is impossible to tell if a person who is in the later stages of dementia is in pain.</li> </ul>	Administration instructions are included on the instrument.	Use the citation provided. No other permissions are required.	The scale is contained within the linked research article.
<a href="#">IDD and Dementia Knowledge Scale</a> (McCallion & Janicki)	20	<ul style="list-style-type: none"> <li>• Aging affects older persons with intellectual disabilities harder than it does other people.</li> <li>• Aging in place means growing older where you are.</li> <li>• As people age, some changes in physical and mental abilities are expected.</li> </ul>	An answer key is included on the instrument.	No special permissions are required.	
<a href="#">Knowledge in Dementia Scale</a> (Elvish et al.)	16	<ul style="list-style-type: none"> <li>• People who have dementia will usually show the same symptoms.</li> <li>• Brain damage is the only factor that is responsible for the way people with dementia behave.</li> <li>• Currently, most types of dementia cannot be cured.</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	

(continued)






**Table 7. Dementia Knowledge and Skills (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Knowledge, Attitude, Practice on Dementia Care (KAP)</a> (Arsenault-Lapierre et al.)	31	<ul style="list-style-type: none"> <li>• Competent to elaborate a care plan</li> <li>• Competent to disclose diagnosis</li> <li>• Know diagnostic criteria</li> <li>• Understand vision and values of the Alzheimer Plan</li> </ul>	Scores are included in the scale; no further instructions are available.	Use the citation provided. No other permissions are required.	General questions in section A may be eliminated. Questions related to the Alzheimer Plan can be adapted to the context of another intervention in dementia care. If there is no intervention, the section can be deleted. A French version is available within the linked scale.






Table 8. Depression

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Center for Epidemiologic Studies Depression Scale Revised (CESD-R)</a>  (Eaton et al.)	5-, 10-, and 20-item versions	In the past week or so: <ul style="list-style-type: none"> <li>• My appetite was poor.</li> <li>• I could not shake off the blues.</li> <li>• I had trouble keeping my mind on what I was doing.</li> </ul>	<a href="#">Scoring instructions</a>  are available.	No special permissions are required.	
<a href="#">Geriatric Depression Scale</a>  (Yesavage et al.)	1-, 4-, 10-, 15-, and 30-item versions	<ul style="list-style-type: none"> <li>• Have you dropped many of your activities and interests?</li> <li>• Are you in good spirits most of the time?</li> <li>• Do you think that most people are better off than you are?</li> </ul>	<a href="#">Short-form</a>  and <a href="#">long-form</a>  scoring instructions and <a href="#">information on handling missing responses</a>  are available.	No special permissions are required.	Translations are available through the <a href="#">GDS website</a> .  iPhone and Android apps are available.
<a href="#">Patient Health Questionnaire (PHQ-9), (PHQ-4)</a>  (Kroenke, Spitzer, & Williams)	4- and 9-item versions	Over the last 2 weeks, how often have you been bothered by any of the following problems? <ul style="list-style-type: none"> <li>• Little interest or pleasure in doing things</li> <li>• Feeling down, depressed, or hopeless</li> </ul>	An <a href="#">instruction manual</a>  is available.	No special permissions are required.	Translations are available through the website.
<a href="#">World Health Organization 5 Well-being Index</a>  (Topp et al.)	5	Over the last 2 weeks: <ul style="list-style-type: none"> <li>• I have felt calm and relaxed.</li> <li>• I woke up feeling fresh and rested.</li> </ul>	Scoring and interpretation instructions are included on the instrument.	No special permissions are required.	Translations are available through the website.

**Table 9. Engagement in Activity(ies)**


Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Assessment of Quality of Activities (A-QOA)</a>  ( <a href="#">Ogawa et al.</a> )	21	<ul style="list-style-type: none"> <li>Initiation: Initiating the activity</li> <li>Gaze: Directing one’s gaze at the activity</li> <li>Satisfaction: Expressing satisfaction as a result of the activity</li> </ul>	<a href="#">Scoring information</a>  is available.	Developers may be contacted at <a href="https://www.a-qa.com/en">https://www.a-qa.com/en</a> . 	The instrument is available in Japanese and English.
<a href="#">Engagement of a Person with Dementia Scale</a>  ( <a href="#">Jones, Sung, &amp; Moyle</a> )	10	<ul style="list-style-type: none"> <li>Displays positive affect such as pleasure, contentment, or excitement.</li> <li>Maintains eye contact with the activity, materials used, or the person/s involved.</li> <li>Appears inattentive, has an unfocused stare, or turns head/eyes away from the activity, materials used, or the person/s involved.</li> </ul>	Administration and scoring instructions are included on the instrument.	The instrument may not be used for commercial purposes.	The scale is contained within the cited research article, which may be obtained for a small fee.
<a href="#">Observable Well-being in Living with Dementia Scale</a>  ( <a href="#">Madsø, Pachana, &amp; Nordhus</a> )	8	Items are scored as “present” or “not present” during 30-second intervals of observation. <ul style="list-style-type: none"> <li>Attention</li> <li>Calm/relaxed</li> <li>Enjoyment</li> </ul>	Scoring instructions are included with the scale.	Use the citation provided. No other permissions are required.	
<a href="#">Observational Measurement of Engagement</a> ( <a href="#">Cohen-Mansfield, Dakheel-Ali, &amp; Marx</a> )	14	<ul style="list-style-type: none"> <li>Attention to stimulus during engagement</li> <li>Attitude to stimulus during engagement</li> <li>Dexterous difficulty with task</li> </ul>	Contact Jiska Cohen-Mansfield at <a href="mailto:jiska@tauex.tau.ac.il">jiska@tauex.tau.ac.il</a> for scoring instructions.	Contact Jiska Cohen-Mansfield at <a href="mailto:jiska@tauex.tau.ac.il">jiska@tauex.tau.ac.il</a> for permission.	

**Table 10. Health and Health Care Utilization**





Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Caregiver Self-Assessment Questionnaire</a>  ( <a href="#">Epstein-Lubow et al.</a> )	18	<ul style="list-style-type: none"> <li>• During the past week or so, I have been edgy or irritable.</li> <li>• During the past week or so, I have felt lonely.</li> <li>• Please rate your current health compared to what it was this time last year.</li> </ul>	Scoring and interpretation instructions are included on the instrument.	Contact <a href="mailto:info@healthinaging.org">info@healthinaging.org</a> for permission.	<a href="#">Translations</a>  are available.
<a href="#">Frailty Index for Elders (FIFE)</a>  ( <a href="#">Tocchi et al.</a> )	10	<ul style="list-style-type: none"> <li>• Do you need help getting out of bed?</li> <li>• Without wanting to, have you lost or gained 10 pounds in the last 6 months?</li> <li>• Do you get tired easily?</li> </ul>	Scoring instructions are included on the instrument.	This material may be used in its entirety for not-for-profit educational purposes only. Cite The Hartford Institute for Geriatric Nursing, New York University, College of Nursing as the source. Email notification of usage to <a href="mailto:hartford.ign@nyu.edu">hartford.ign@nyu.edu</a> .	
<a href="#">Patient-Reported Outcomes Measurement Information System (PROMIS) Global Health Scale</a>  ( <a href="#">Hays et al.</a> )	10	<ul style="list-style-type: none"> <li>• To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?</li> <li>• How would you rate your fatigue on average?</li> <li>• In general, how would you rate your physical health?</li> </ul>	Administration instructions are included on the instrument.	No permissions are required for use in individual research, clinical practice, or educational assessment. Commercial users must seek permission. <a href="#">Additional permissions information</a>  is available.	

(continued)

**Table 10. Health and Health Care Utilization (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Stanford Health Care Utilization Questionnaire (SHCUQ)</a>  (Lorig et al.)	4	In the past 6 months <ul style="list-style-type: none"> <li>• How many times did you visit a physician?</li> <li>• How many different times did you stay in a hospital overnight or longer?</li> </ul>	Administration instructions are included on the instrument.	No special permissions are required.	





**Table 11. Quality of Life and Well-Being**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Adult Social Care Outcomes Toolkit – Carer (ASCOT) (Carer SCT4 or Carer INT4)</a>  (Rand et al.)	7	Which of the following statements best describes... <ul style="list-style-type: none"> <li>• How you spend your time</li> <li>• How safe you feel</li> </ul>	Administration and scoring information are provided with registration to use the tool.	ASCOT is free of charge for not-for-profit use, but a <a href="#">license is required</a> . 	
<a href="#">Caregiver Well-Being Scale (Tebb, Berg-Weger, &amp; Rubio)</a>	14- or 45-item versions	To what extent has each activity been taken care of in a timely way: <ul style="list-style-type: none"> <li>• Taking care of personal daily activities (meals, hygiene, laundry)</li> <li>• Attending to medical needs</li> <li>• Taking time to have fun with friends and/or family</li> </ul>	No scoring instructions are provided.	Contact Susan Tebb at <a href="mailto:tebbsc@slu.edu">tebbsc@slu.edu</a> for permission.	
<a href="#">Control, Autonomy, Self-Realization and Pleasure Scale (CASP-19)</a>  (Stoner, Orrell, & Spector)	19	<ul style="list-style-type: none"> <li>• My health stops me from doing things I want to do.</li> <li>• I enjoy being in the company of others.</li> <li>• I feel that life is full of opportunities.</li> </ul>	Partial scoring information is available in the cited article.	No special permissions are required.	
<a href="#">Cornell-Brown Scale for Quality of Life in Dementia (CBS-QoLD)</a>  (Ready et al.)	19	<ul style="list-style-type: none"> <li>• Anxiety vs. comfort</li> <li>• Lack of reactivity vs. enjoyment of life’s positive events</li> <li>• Pessimism vs. optimism</li> </ul>	Administration and scoring instructions are provided with purchase.	Permission for use is provided with purchase of the instrument.	A nominal fee is charged for use.

(continued)







**Table 11. Quality of Life and Well-Being (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Dementia Quality of Life (DEMQOL)</a>  (Smith et al.)	28 (PLWD version) or 31 (care partner version)	In the last week: <ul style="list-style-type: none"> <li>• Have you felt cheerful?</li> <li>• How worried have you been about forgetting who people are?</li> <li>• How worried have you been about your health overall?</li> </ul>	Administration instructions are included on the instrument. An <a href="#">interviewer manual</a>  is also available.	Use the citation provided. No other permissions are required.	<a href="#">Translations in Japanese and Spanish</a>  are available.
<a href="#">Engagement and Independence in Dementia Questionnaire (EID-Q)</a> (Stoner, Orrell, & Spector)	26	<ul style="list-style-type: none"> <li>• I can make my own decisions as much as I'd like to.</li> <li>• I can do activities that are important to me.</li> <li>• I can take part in groups/activities with others.</li> </ul>	Administration and scoring instructions are included on the instrument.	The EID-Q is free to use with citation. See the instrument for additional permissions information.	
<a href="#">IDEAL My Life Questionnaire</a>  (Clare et al.)	10	<ul style="list-style-type: none"> <li>• I keep my mind occupied.</li> <li>• I have people to talk to.</li> <li>• I usually sleep well.</li> </ul>	Scoring instructions are included with the scale.	No special permissions are required.	The scale is intended for people living with dementia.




(continued)

**Table 11. Quality of Life and Well-Being (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Patient-Reported Outcomes Measurement Information System (PROMIS) Global Health Scale</a>  (Hays et al.)	10	<ul style="list-style-type: none"> <li>In general, would you say your quality of life is...</li> <li>In general, how would you rate your satisfaction with your social activities and relationships?</li> <li>How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?</li> </ul>	Administration instructions are included on the instrument.	No permissions are required for use in individual research, clinical practice, or educational assessment. Commercial users must seek permission. <a href="#">Additional permissions information</a>  is available.	
<a href="#">Perceived Change Index</a> (Gitlin et al.)	13	Caregiver indicates whether item has become worse, stayed the same, or improved in the past month: <ul style="list-style-type: none"> <li>Your feelings of being overwhelmed</li> <li>Your feelings that things have been going your way</li> <li>Your ability to have time for yourself</li> </ul>	Scoring instructions are available from the NADRC.	Notify Laura Gitlin at <a href="mailto:lng45@drexel.edu">lng45@drexel.edu</a> of use. No other permissions are required.	
<a href="#">Personal Wellbeing Index</a>  ( <a href="#">International Wellbeing Group</a> )	7	<ul style="list-style-type: none"> <li>How satisfied are you with your standard of living?</li> <li>How satisfied are you with your health?</li> </ul>	Administration and scoring instructions are available in the linked manual.	The instrument may not be used for commercial purposes.	Translations are available through the <a href="#">ACQOL website</a> . 










(continued)

**Table 11. Quality of Life and Well-Being (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Positive Psychology Outcome Measure for Carers (PPOM-C)</a> (Pione et al.)	14	<ul style="list-style-type: none"> <li>• My life has value and worth.</li> <li>• I am an emotionally strong person.</li> <li>• I have a positive outlook on life.</li> </ul>	Scoring instructions are included on the instrument.	No amendments should be made to item wording or the Likert scale without permission from the measure authors. Please inform Charlotte Stoner at <a href="mailto:positivepsychology.dementia@gmail.com">positivepsychology.dementia@gmail.com</a> of how the measure is used and contact her about amendments or translations.	
<a href="#">Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP)</a> (Burgener, Twigg, & Popovich)	11	<ul style="list-style-type: none"> <li>• Smiles or laughs in response to contact from others</li> <li>• Listless, resists involvement in activity</li> <li>• Asks repeatedly to go elsewhere</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	
<a href="#">Quality of Life in Alzheimer's Disease (QOL-AD)</a>  (Logsdon et al.)	13	<ul style="list-style-type: none"> <li>• How do you feel about your energy level?</li> <li>• How about your living situation?</li> <li>• How about your ability to do things for fun, that you enjoy?</li> </ul>	Administration and scoring instructions are included on the instrument.	Physicians, clinical practices, and unfunded academic users may obtain the instrument at no cost. Additional permissions information is available from <a href="#">Mapi Research Trust</a> . 	Translations are available through the <a href="#">Mapi Research Trust website</a> . 

(continued)




**Table 11. Quality of Life and Well-Being (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Quality of Life in Late-Stage Dementia</a>  <a href="#">(QUALID) Scale</a>  <a href="#">(Weiner et al.)</a>	11	Example: Enjoys eating <ul style="list-style-type: none"> <li>At most meals and snacks</li> <li>Twice a day</li> <li>At least once a day</li> <li>Less than once a day</li> <li>Rarely or never</li> </ul>	Administration and scoring instructions are included on the instrument.	Contact Myron Weiner at <a href="mailto:Myron.Weiner@UTSouthwestern.edu">Myron.Weiner@UTSouthwestern.edu</a> for permission.	
Saint Louis University Quality of Life Questionnaire in Older Adults with Alzheimer's Disease <a href="#">(Yamashita et al.)</a>	6	<ul style="list-style-type: none"> <li>My quality of life is...</li> <li>My ability to tolerate my illnesses is...</li> <li>My energy is...</li> </ul>	Scoring instructions are available in the original article.	Contact Kyla Yamashita at <a href="mailto:kyla.yamashita@health.slu.edu">kyla.yamashita@health.slu.edu</a> for permission.	The scale is available in the cited research article.
<a href="#">Warwick-Edinburgh Mental Well-being Scale</a>  <a href="#">(WEMWBS)</a>  <a href="#">(Tennant et al.)</a>	7 or 14	<ul style="list-style-type: none"> <li>I've been feeling optimistic about the future.</li> <li>I've been dealing with problems well.</li> <li>I've been feeling close to other people.</li> </ul>	<a href="#">Scoring and analysis instructions</a>  are available.	Information on <a href="#">permissions and usage licenses</a>  are available.	The scale has been translated in <a href="#">over 25 languages</a> . 
<a href="#">World Health Organization 5 Well-being Index</a>  <a href="#">(Topp et al.)</a>	5	Over the last 2 weeks: <ul style="list-style-type: none"> <li>I have felt calm and relaxed.</li> <li>I woke up feeling fresh and rested.</li> </ul>	Scoring and interpretation instructions are included on the instrument.	No special permissions are required.	Translations are available through <a href="#">the WHO-5 website</a> . 

**Table 12. Quality of Life for People with Intellectual and Developmental Disabilities**


Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Dementia Quality of Life (DEMQOL)</a> <a href="#">↗</a> ( <a href="#">Smith et al.</a> )	28 (PLWD version) or 31 (care partner version)	In the last week: <ul style="list-style-type: none"> <li>• Have you felt cheerful?</li> <li>• How worried have you been about forgetting who people are?</li> <li>• How worried have you been about your health overall?</li> </ul>	Administration instructions are included on the instrument. An <a href="#">interviewer manual</a> <a href="#">↗</a> is also available.	Use the citation provided. No other permissions are required.	<a href="#">Translations in Japanese and Spanish</a> <a href="#">↗</a> are available.
<a href="#">Quality of Life in Alzheimer’s Disease (QOL-AD)</a> <a href="#">↗</a> ( <a href="#">Logsdon et al.</a> )	13	<ul style="list-style-type: none"> <li>• How do you feel about your energy level?</li> <li>• How about your living situation?</li> <li>• How about your ability to do things for fun, that you enjoy?</li> </ul>	Administration and scoring instructions are included on the instrument.	Physicians, clinical practices, and unfunded academic users may obtain the instrument at no cost. Additional permissions information is available from <a href="#">Mapi Research Trust</a> . <a href="#">↗</a>	Translations are available through the <a href="#">Mapi Research Trust website</a> . <a href="#">↗</a>
<a href="#">Quality of Life in Late-Stage Dementia Scale (QUALID)</a> <a href="#">↗</a> ( <a href="#">Weiner et al.</a> )	11	Example: Enjoys eating <ul style="list-style-type: none"> <li>• At most meals and snacks</li> <li>• Twice a day</li> <li>• At least once a day</li> <li>• Less than once a day</li> <li>• Rarely or never</li> </ul>	Administration and scoring instructions are included on the instrument.	Contact Myron Weiner at <a href="mailto:Myron.Weiner@UTSouthwestern.edu">Myron.Weiner@UTSouthwestern.edu</a> for permission.	

**Table 13. Risk Assessment and Safety**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Care Needs Assessment Tool</a>  (Alzheimer's Los Angeles)	23	<ul style="list-style-type: none"> <li>• Insists on driving</li> <li>• Takes medicine the wrong way</li> </ul>	Administration and scoring instructions are included on the instrument.	Use the following citation. No other permissions are required. Materials reproduced/adapted with permission from Alzheimer's Los Angeles. © 2016 Alzheimer's Los Angeles	
<a href="#">Caregiver Risk Appraisal Questionnaire (REACH II)</a>  (Wisniewski et al.)	16	<ul style="list-style-type: none"> <li>• Do you ever leave [Care recipient] alone or unsupervised in the home?</li> <li>• Does [Care recipient] drive?</li> <li>• Can [Care recipient] get to dangerous objects (e.g., loaded or unlocked gun, or sharp objects that are used as weapons)?</li> </ul>	Scoring instructions are included on the instrument.	Use the citation provided. No other permissions are required.	
<a href="#">Dementia Crisis to Thriving Scale</a>  (Weaver & Samia)	13	<p>Falls Risk:</p> <ul style="list-style-type: none"> <li>• Falls 2 or more times in past month, with injury. Home is unsafe.</li> <li>• Home unsafe. Fall without injury, or no fall in past 3 months.</li> <li>• Home is safe. Fall within 3–5 months, no injury. Fall risk factors exist.</li> <li>• No falls in past 6 months, home is safe, no fall risk factors.</li> <li>• No falls in past 12 months, gait stable, active, safe home.</li> </ul>	No scoring instructions are provided.	No special permissions are required.	

(continued)

**Table 13. Risk Assessment and Safety (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Live Alone Assessment</a> ( <a href="#">Hall, Bossen, &amp; Specht</a> )	29	Observed or reported conditions during a home visit: <ul style="list-style-type: none"> <li>Wandering outside the home</li> <li>Inability to take medications correctly</li> <li>Dirty/infested household</li> </ul>	Scoring instructions are included on the instrument.	Permission has been obtained for ACL grantees. All other users should contact the developer.	
<a href="#">Quality of Care – Living Environment (REACH II)</a>  ( <a href="#">Wisniewski et al.</a> )	14	<ul style="list-style-type: none"> <li>Do you keep materials present to occupy CR or that provide comfort or meaning (e.g., games, sorting tasks, magazines, photos, stuffed animals)?</li> <li>Observe: Objects on floor or pathways in main areas used by (care recipient)</li> <li>Do you have a grab bar in the bathroom primarily used by (care recipient)?</li> </ul>	Administration instructions are included on the instrument.	Use the citation provided. No other permissions are required.	

**Table 14. Self-Efficacy**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Brief Tool for Dementia Friendly Educational and Training Sessions (BTDF)</a> (Menne & Guerrero)	7	<ul style="list-style-type: none"> <li>I am confident interacting with people with dementia.</li> <li>I can respond to people with dementia with understanding.</li> </ul>	Administration and scoring instructions are included on the instrument.	No special permissions are required.	Versions are available for individual or organizational trainings.
<a href="#">Caregiver Outcomes of Psychotherapy Evaluation (COPE)</a> (Aguirre et al.)	8	<ul style="list-style-type: none"> <li>I am knowledgeable about dementia (symptoms, stages, behaviors).</li> <li>I have a network of people who provide me with practical and emotional support.</li> <li>I am confident in my caregiving skills.</li> </ul>	Scoring instructions are included with the research article.	Please notify Alyssa Aguirre of use at <a href="mailto:alyssa.aguirre@austin.utexas.edu">alyssa.aguirre@austin.utexas.edu</a> and use the citation provided. No other permissions are required.	
<a href="#">Confidence in Dementia Scale (CODES)</a> (Elvish et al.)	9	<ul style="list-style-type: none"> <li>I feel able to identify when a person may have dementia.</li> <li>I feel able to gather relevant information to understand the needs of a person with dementia.</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	

(continued)




Table 14. Self-Efficacy (continued)




Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
Fortinsky Caregiver Self-Efficacy ( <a href="#">Fortinsky, Kercher, &amp; Burant</a> )	10	How certain are you right now that you can... <ul style="list-style-type: none"> <li>• Handle any problems your relative has, like memory loss, wandering, or behavior problems?</li> <li>• Do something to keep your relative as independent as possible?</li> <li>• Find organizations or agencies in the community that provide services to help you care for your relative?</li> </ul>	No scoring instructions are provided.	Notify Richard Fortinsky at <a href="mailto:fortinsky@uchc.edu">fortinsky@uchc.edu</a> of use. No other permissions are required.	Items and response options are listed in the research article, which may be purchased online.
<a href="#">General Practitioners' Attitudes and Confidence towards Dementia Survey (GPACS-D)</a> ( <a href="#">Mason, Doherty, &amp; Eccleston</a> )	15	<ul style="list-style-type: none"> <li>• I feel frustrated because I do not know how to effectively treat people with dementia.</li> <li>• I feel confident in my ability to provide advice about managing dementia-related symptoms.</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	Select items may need to be edited for a U.S. audience.
<a href="#">Perceived Change Index</a> ( <a href="#">Gitlin et al.</a> )	13	Caregiver indicates whether each item has become worse, stayed the same, or improved in the past month: <ul style="list-style-type: none"> <li>• Your ability to understand your [CR's] behavior</li> <li>• Your ability to manage day-to-day caregiving</li> <li>• Your feelings of being overwhelmed</li> </ul>	Scoring instructions are available from the NADRC.	Notify Laura Gitlin at <a href="mailto:lng45@drexel.edu">lng45@drexel.edu</a> of use. No other permissions are required.	

(continued)

**Table 14. Self-Efficacy (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Preparedness for Caregiving Scale (PCS)</a>  (Archbold et al.)	9	<ul style="list-style-type: none"> <li>How well prepared do you think you are to take care of your family member's physical needs?</li> <li>How well prepared do you think you are to find out about and set up services for him or her?</li> </ul>	Scoring instructions are provided on the instrument.	Cite the source. No other permissions are required.	
<a href="#">Sense of Competence in Dementia Care Staff Scale (SCIDS)</a> (Schepers et al.)	17	How well do you feel you can: <ul style="list-style-type: none"> <li>Engage a person with dementia in a conversation?</li> <li>Change your work to match the changing needs of a person with dementia?</li> <li>Keep up a positive attitude towards the people you care for?</li> </ul>	Scoring instructions are included on the instrument.	The measure is free to use.	

**Table 15. Social Isolation and Wellness**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">BRI Social Isolation Scale</a> ( <a href="#">Bass et al.</a> )	7	Because of my (RELATIONSHIP)'s illness and care: <ul style="list-style-type: none"> <li>I felt isolated from other people.</li> <li>I engaged in fewer volunteer activities.</li> </ul>	Administration and scoring instructions are included on the instrument.	Contact David Bass for permission at <a href="mailto:dbass@benrose.org">dbass@benrose.org</a> .	
<a href="#">De Jong Gierveld Loneliness Scale</a>  ( <a href="#">de Jong Gierveld &amp; van Tilburg</a> )	6	<ul style="list-style-type: none"> <li>I experience a general sense of emptiness.</li> <li>There are many people I can trust completely.</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	
<a href="#">Engagement and Independence in Dementia Questionnaire (EID-Q)</a> ( <a href="#">Stoner, Orrell, &amp; Spector</a> )	26	<ul style="list-style-type: none"> <li>I enjoy conversations with others.</li> <li>I can confide in my friends/family.</li> <li>There are people I could ask for help if I need to.</li> </ul>	Administration and scoring instructions are included on the instrument.	The EID-Q is free to use with citation. See the instrument for additional permissions information.	
<a href="#">Multidimensional Scale of Perceived Social Support</a>  ( <a href="#">Zimet et al.</a> )	12	<ul style="list-style-type: none"> <li>There is a special person who is around when I am in need.</li> <li>There is a special person with whom I can share joys and sorrows.</li> <li>My family really tries to help me.</li> </ul>	Scoring instructions are included on the instrument. More information is available <a href="#">at this website</a> . 	Use the citation provided. No other permissions are required.	

(continued)

**Table 15. Social Isolation and Wellness (continued)**







Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">The Campaign to End Loneliness Measurement Tool</a>  (Campaign to End Loneliness)	3	<ul style="list-style-type: none"> <li>• I am content with my friendships and relationships.</li> <li>• I have enough people I feel comfortable asking for help at any time.</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	This tool has been validated, but the research is not published. For more information, contact Campaign to End Loneliness at <a href="mailto:info@campaigntoendloneliness.org.uk">info@campaigntoendloneliness.org.uk</a> .
<a href="#">UCLA Loneliness Scale</a>  (Hughes et al.)	3	<ul style="list-style-type: none"> <li>• How often do you feel that you lack companionship?</li> <li>• How often do you feel left out?</li> </ul>	Scoring instructions are included on the instrument.	No special permissions are required.	

Table 16. Unmet Needs

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Care Needs Assessment Tool</a>  ( <a href="#">Alzheimer's Los Angeles</a> )	23	Has the caregiver experienced this? <ul style="list-style-type: none"> <li>• Difficulty providing care because of own health</li> <li>• Lacks understanding of dementia</li> <li>• Long-term care planning</li> </ul>	Administration and scoring instructions are included on the instrument.	Use the following citation. No other permissions are required. Materials reproduced/adapted with permission from Alzheimer's Los Angeles. © 2016 Alzheimer's Los Angeles	
<a href="#">Dementia Carer Assessment of Support Needs Tool (DeCANT)</a>  ( <a href="#">Clemmensen et al.</a> )	25	Do you have a need for support... <ul style="list-style-type: none"> <li>• to manage everyday chores?</li> <li>• to prioritize your own health?</li> <li>• to manage financial issues on behalf of the person with dementia?</li> </ul>	Scoring instructions are included in the <a href="#">DeCANT manual</a> . 	DeCANT may not be modified but may be used free of charge for clinical and scientific purposes according to the specifications outlined in the manual.	Users who wish to translate the scale or adapt it culturally should contact Trine Holt Clemmensen at <a href="mailto:thcl@ucl.dk">thcl@ucl.dk</a> .
<a href="#">Desire to Institutionalize Scale (DIS)</a>  ( <a href="#">Morycz</a> )	6	<ul style="list-style-type: none"> <li>• Have you ever considered or thought about a nursing home for your family member now or for the future?</li> <li>• Have you ever felt that someday they might be better off in a nursing home?</li> </ul>	Total score is calculated by summing responses across questions, unweighted. Scores range from 0 to 6, with higher scores indicating greater desire to institutionalize.	Use the citation provided. No other permissions are required.	

(continued)

**Table 16. Unmet Needs (continued)**

Instrument	Number of items	Sample item(s)	Instructions	Permissions	Notes
<a href="#">Formal Care and Services Use (REACH II)</a> <a href="#">↗</a> ( <a href="#">Wisniewski et al.</a> )	22	In the past month, did you or (care recipient): <ul style="list-style-type: none"> <li>• Have a homemaker who helped with shopping, cleaning, laundry, preparing meals, etc.?</li> <li>• Go to a center for low-cost meals or have cooked meals delivered to you at home?</li> <li>• Attend a senior day care or senior day health program?</li> </ul>	Administration instructions are included on the instrument.	Use the citation provided. No other permissions are required.	
<a href="#">Managing Your Own Health (MYOH)/</a> <a href="#">Managing Your Loved One's Health (MYLOH)</a> <a href="#">↗</a> ( <a href="#">Sadak, Korpak, &amp; Borson</a> )	32 (PLWD version); 34 (care partner version)	I want to talk about: <ul style="list-style-type: none"> <li>• How to get information about what to expect as dementia progresses</li> <li>• How to get help with caregiving</li> <li>• How to get help paying for basics for myself</li> </ul>	This instrument is not scored; it is used to identify areas of need.	Permissions are not required for clinical or educational use. Additional information is available through the <a href="#">MYLOH website</a> . <a href="#">↗</a>	
Unmet Needs ( <a href="#">Bass et al.</a> )	49	Do you need more information about or help with this? <ul style="list-style-type: none"> <li>• Planning who would help your (RELATIONSHIP) if you were no longer able to help?</li> <li>• Getting information about your (RELATIONSHIP)'s memory problems?</li> <li>• Ways to make the place where your (RELATIONSHIP) lives safe?</li> </ul>	This instrument is not scored; it is used to identify areas of need.	Contact David Bass at <a href="mailto:dbass@benrose.org">dbass@benrose.org</a> for permission.	Instrument is available upon request from the NADRC.

## References

- Aguirre, A., Benge, J. F., Finger, A. H., Ambiee, J., Runnels, I., & Hilsabeck, R. C. (2024). The Caregiver Outcomes of Psychotherapy Evaluation (COPE): Development of a social work assessment tool. *Clinical Social Work Journal*, 1–10.  
<https://doi.org/10.1007/s10615-024-00925-2>
- Albert, M., & Cohen, C. (1992). The Test for Severe Impairment: An instrument for the assessment of patients with severe cognitive dysfunction. *Journal of the American Geriatrics Society*, 40(5), 449–453. <https://doi.org/10.1111/j.1532-5415.1992.tb02009.x>
- Alzheimer's Greater Los Angeles. (2016). *Care Needs Assessment Tool*. Retrieved from <https://www.alz gla.org/wp-content/uploads/2017/01/Care-Needs-Assessment-Tool.pdf>
- Annear, M., Toye, C., Eccleston, C., McInerney, F., Elliott, K., Tranter, B., ... Robinson, A. L. (2015). Dementia Knowledge Assessment Scale: Development and preliminary psychometric properties. *Journal of the American Geriatrics Society*, 63(11), 2375–2381. <https://doi.org/10.1111/jgs.13707>
- Archbold, P., Stewart, B., Greenlick, M., & Harvath, T. (1992). The clinical assessment of mutuality and preparedness in family caregivers to frail older people. In S. G. Funk, E. M. Tornquist, M. T. Champagne, & L. A. Copp (Eds.), *Key aspects of elder care* (pp. 328–339). New York: Springer.
- Arsenault-Lapierre, G., Sourial, N., Pakzad, S., Hardouin, M., Couturier, Y., Bergman, H., & Vedel, I. (2021). Validation of a questionnaire for family physicians: Knowledge, attitude, practice on dementia care. *Canadian Journal on Aging*, 40(2), 238–247. <https://doi.org/10.1017/S0714980820000069>
- Basic, D., Rowland, J. T., Conforti, D. A., Vratsidis, F., Hill, K., LoGiudice, D., ... Prowse, R. J. (2009). The validity of the Rowland Universal Dementia Assessment Scale (RUDAS) in a multicultural cohort of community-dwelling older persons with early dementia. *Alzheimer Disease & Associated Disorders*, 23(2), 124–129. <https://doi.org/10.1097/wad.0b013e31818ecc98>
- Bass, D. M., Hornick, T., Kunik, M., Judge, K. S., Primetica, B., Kearney, K., ... Grim, J. (2019). Findings from a real-world translation study of the evidence-based “Partners in Dementia Care.” *Innovation in Aging*, 3(3). <https://doi.org/10.1093/geroni/igz031>
- Bass, D., Judge, K., Snow, A., Wilson, N., Looman, W., McCarthy, C., ... Kunik, M. (2012). Negative caregiving effects among caregivers of veterans with dementia. *American Journal of Geriatric Psychiatry*, 20(3), 239–247. <https://doi.org/10.1097/JGP.0b013e31824108ca>

## References

- Bédard, M., Molloy, D., Squire, L., Dubois, S., Lever, J., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41(5), 652–657. <https://doi.org/10.1093/geront/41.5.652> ↗
- Bhatt, J., Brohan, E., Blasco, D., Oliveira, D., Bakolis, I., Comas-Herrera, A., ... Evans-Lacko, S. (2023). The development and validation of the Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia). *BJPsych Open*, 9(5), e164. <https://doi.org/10.1192/bjo.2023.551> ↗
- Borson, S., Scanlan, J., Brush, M., Vitaliano, P., & Dokmak, A. (2000). The mini-cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry*, 15(11), 1021–1027. [https://doi.org/10.1002/1099-1166\(200011\)15:11%3C1021::aid-gps234%3E3.0.co;2-6](https://doi.org/10.1002/1099-1166(200011)15:11%3C1021::aid-gps234%3E3.0.co;2-6) ↗
- Burgener, S. C., Twigg, P., & Popovich, A. (2005). Measuring psychological well-being in cognitively impaired persons. *Dementia*, 4(4), 463–485. <https://doi.org/10.1177/1471301205058303> ↗
- Campaign to End Loneliness. (2015). *Measuring your impact on loneliness in later life*. Retrieved from <https://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-Measurement-Guidance1.pdf> ↗
- Chao, H. C., Yang, Y. P., Huang, M. C., & Wang, J. J. (2016). Development and psychometric testing of the Caregiver Communication Competence Scale in patients with dementia. *Journal of Gerontological Nursing*, 42(1), 32–39. <https://doi.org/10.3928/00989134-20151008-36> ↗
- Clare, L., Pentecost, C., Collins, R., Martyr, A., Litherland, R., Morris, R. G., ... Victor, C. (2023). Evaluating 'living well' with mild-to-moderate dementia: Co-production and validation of the IDEAL My Life Questionnaire. *Dementia*, 22(7), 1548–1566. <https://doi.org/10.1177/14713012231188502> ↗
- Clemmensen, T. H., Kristensen, H. K., Andersen-Ranberg, K., & Lauridsen, H. H. (2021). Development and field-testing of the Dementia Carer Assessment of support Needs Tool (DeCANT). *International Psychogeriatrics*, 33(4), 405–417. <https://doi.org/10.1017/S1041610220001714> ↗
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24(4), 385–396.
- Cohen-Mansfield, J., Dakheel-Ali, M., & Marx, M. S. (2009). Engagement in persons with dementia: The concept and its measurement. *American Journal of Geriatric Psychiatry*, 17(4), 299–307. <https://doi.org/10.1097/JGP.0b013e31818f3a52> ↗



- Cummings, J. (1997). The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology*, *48*(Suppl 6), S10–S16.  
[https://doi.org/10.1212/wnl.48.5\\_suppl.6.10s](https://doi.org/10.1212/wnl.48.5_suppl.6.10s) ↗
- de Jong Gierveld, J., & van Tilburg, T. (2006). 6-Item Scale for Overall, Emotional, and Social Loneliness: Confirmatory tests on survey data. *Research on Aging*, *28*(5), 582–598.  
<https://doi.org/10.1177/0164027506289723> ↗
- Deb, S., Hare, M., Prior, L., & Bhaumik, S. (2007). Dementia screening questionnaire for individuals with intellectual disabilities (DSQIID). *British Journal of Psychiatry*, *190*, 440–444. <https://doi.org/10.1192/bjp.bp.106.024984> ↗
- Eaton, W. W., Smith, C., Ybarra, M., Muntaner, C., & Tien, A. (2004). Center for Epidemiologic Studies Depression Scale: Review and revision (CESD and CESD-R). In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment* (3rd ed.), Volume 3: Instruments for adults, pp. 363–377. Mahwah, NJ: Lawrence Erlbaum.
- Elvish, R., Burrow, S., Cawley, R., Harney, K., Pilling, M., Gregory, J., & Keady, J. (2018). ‘Getting to Know Me’: The second phase roll-out of a staff training programme for supporting people with dementia in general hospitals. *Dementia*, *17*, 96–109.  
<https://doi.org/10.1177/1471301216634926> ↗
- Epstein-Lubow, G., Gaudiano, B. A., Hinckley, M., Salloway, S., & Miller, I. W. (2010). Evidence for the validity of the American Medical Association’s caregiver self-assessment questionnaire as a screening measure for depression. *Journal of the American Geriatrics Society*, *58*(2), 387–388. <https://doi.org/10.1111/j.1532-5415.2009.02701.x> ↗
- Farran, C. J., Fogg, L. G., McCann, J. J., Etkin, C., Dong, X., & Barnes, L. L. (2011). Assessing family caregiver skill in managing behavioral symptoms of Alzheimer’s disease. *Aging & Mental Health*, *15*(4), 510–521.  
<https://doi.org/10.1080/13607863.2010.536140> ↗
- Fife, B., & Wright, E. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, *41*(1), 50–67.
- Fortinsky, R. H., Kercher, K., & Burant, C. J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health*, *6*(2), 153–160. <https://doi.org/10.1080/13607860220126763> ↗
- Galvin, J., Roe, C., Powlishta, K., Coats, M., Muich, S., Grant, E., ... Morris, J. (2005). The AD8, a brief informant interview to detect dementia. *Neurology*, *65*(4), 559–564.  
<https://doi.org/10.1212/01.wnl.0000172958.95282.2a> ↗

## References

- Gitlin, L., Winter, L., Dennis, M., & Hauck, W. (2006). Assessing perceived change in the well-being of family caregivers: Psychometric properties of the Perceived Change Index and response patterns. *American Journal of Alzheimer's Disease & Other Dementias*, 21(5), 304–311. <https://doi.org/10.1177/1533317506292283> ↗
- Graessel, E., Berth, H., Lichte, T., & Grau, H. (2014). Subjective caregiver burden: Validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics*, 20, 14–23. <https://doi.org/10.1186/1471-2318-14-23> ↗
- Hall, G., Bossen, A., & Specht, J. (2004). *Live Alone Assessment*. Iowa City, Iowa: The University of Iowa College of Nursing.
- Hays, R. D., Bjorner, J. B., Revicki, D. A., Spritzer, K. L., & Cella, D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research*, 18(7), 873–880. <https://doi.org/10.1007/s11136-009-9496-9> ↗
- Hopkins, R. W., & Kilik, L. A. (2013). The mini-Kingston Standardized Cognitive Assessment. *American Journal of Alzheimer's Disease and Other Dementias*, 28, 239–244. <https://doi.org/10.1177/1533317513481095> ↗
- Hughes, M. E., Waite, L. J., Hawkey, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on Aging*, 26(6), 655–672. <https://doi.org/10.1177/0164027504268574> ↗
- International Wellbeing Group. (2013). *Personal Wellbeing Index* (5th ed.). Melbourne: Australian Centre on Quality of Life, Deakin University.
- Jones, C., Sung, B., & Moyle, W. (2018). Engagement of a Person with Dementia Scale: Establishing content validity and psychometric properties. *Journal of Advanced Nursing*. <https://doi.org/10.1111/jan.13717> ↗
- Jørgensen, K., Nielsen, T. R., Nielsen, A., Waldorff, F. B., & Waldemar, G. (2020). Brief Assessment of Impaired Cognition Questionnaire (BASIC-Q)—Development and validation of a new tool for identification of cognitive impairment in community settings. *International Journal of Geriatric Psychiatry*, 35(7), 693–701. <https://doi.org/10.1002/gps.5286> ↗
- Jorm, A. F. (1994). A short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): Development and cross validation. *Psychological Medicine*, 24(1), 145–153. <https://doi.org/10.1017/s003329170002691x> ↗
- Kay, D. W. K., Tyrer, S. P., Margallo-Lana, M. L., Moore, P. B., Fletcher, R., Berney, T. P., & Vithayathil, E. (2003). Preliminary evaluation of a scale to assess cognitive function in adults with Down's syndrome: The Prudhoe Cognitive Function Test. *Journal of Intellectual Disability Research*, 47(Pt 3), 155–168. <https://doi.org/10.1046/j.1365-2788.2003.00451.x> ↗

- Kroenke, K., Spitzer, R., & Williams, J. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606–613.  
<https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Kroenke, K., Spitzer, R., Williams, J., & Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*, *50*(6), 613–621.  
<https://doi.org/10.1176/appi.psy.50.6.613>
- Lipton, R. B., Katz, M. J., Kuslansky, G., Sliwinski, M. J., Stewart, W. F., Verghese, J., ... Buschke, H. (2003). Screening for dementia by telephone using the Memory Impairment Screen. *Journal of the American Geriatrics Society*, *51*(10), 1382–1390.  
<https://doi.org/10.1046/j.1532-5415.2003.51455.x>
- Logsdon, R., Gibbons, L., McCurry, S., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, *64*(3), 510–519.  
<https://doi.org/10.1097/00006842-200205000-00016>
- Lorig, K., Stewart, A., Ritter, P., González, V., Laurent, D., & Lynch, J. (1996). Stanford Chronic Disease Self-Management Study. In *Outcome measures for health education and other health care interventions* (pp. 24–25). Thousand Oaks, CA: Sage Publications.
- Macera, C. A., Eaker, E. D., Jannarone, R. J., Davis, D. R., & Stoskopf, C. H. (1993). A measure of perceived burden among caregivers. *Evaluation & the Health Professions*, *16*(2), 205–211.
- Madsø, K. G., Pachana, N. A., & Nordhus, I. H. (2023). Development of the Observable Well-Being in Living With Dementia-Scale. *American Journal of Alzheimer's Disease and Other Dementias*, *38*. <https://doi.org/10.1177/15333175231171990>
- Mason, R., Doherty, K., Eccleston, C., Annear, M., Lo, A., Tierney, L., McInerney, F., & Robinson, A. (2019). General practitioners attitude and confidence scale for dementia (GPACS-D): Confirmatory factor analysis and comparative subscale scores among GPs and supervisors. *BMC Family Practice*, *20*, 6.  
<https://doi.org/10.1186/s12875-018-0896-1>
- McCallion, P., & Janicki, M. (2000). *IDD and Dementia Knowledge Scale*. Center on Intellectual Disabilities, University at Albany.
- Meichsner, F., Schinköthe, D., & Wilz, G. (2016). The Caregiver Grief Scale: Development, exploratory and confirmatory factor analysis, and validation. *Clinical Gerontologist*, *39*(4), 342–361. <https://doi.org/10.1080/07317115.2015.1121947>
- Menne, H., & Guerrero, L. (2019). *Measuring the impact of dementia-friendly education and training sessions: A toolkit*. Prepared for U.S. Administration for Community Living. Retrieved from <https://nadrc.acl.gov/details?search1=172#result>

## References

- Mills, W., Regev, T., Kunik, M., Wilson, N., Moye, J., McCullough, L., & Naik, A. (2014). Making and Executing Decisions for Safe and Independent Living (MED-SAIL): Development and validation of a brief screening tool. *American Journal of Geriatric Psychiatry*, 22(3), 285–293. <https://doi.org/10.1016/j.jagp.2012.08.016>
- Morycz, R. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging*, 7(3), 329–361. <https://doi.org/10.1177/0164027585007003002>
- Nasreddine, Z., Phillips, N., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., ... Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695–699. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>
- O'Connor, M., & McFadden, S. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*. <https://doi.org/10.4061/2010/454218>
- Ogawa, M., Shirai, H., Nishida, S., & Tanimukai, H. (2021). Rasch analysis of the Assessment of Quality of Activities (A-QOA), an observational tool for clients with dementia. *American Journal of Occupational Therapy*, 75(1). <https://doi.org/10.5014/ajot.2021.039917>
- Pfeffer, R., Kurosaki, T., Harrah, C., Chance, J., & Filos, S. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology*, 37(3), 323–329. <https://doi.org/10.1093/geronj/37.3.323>
- Pione, R. D., Stoner, C. R., Cartwright, A. V., & Spector, A. (2023). Measuring hope and resilience in carers of people living with dementia: The Positive Psychology Outcome Measure for Carers (PPOM-C). *Dementia*, 22(5), 978–994. <https://doi.org/10.1177/14713012231165113>
- Prasher, V., Farooq, A., & Holder, R. (2004). The Adaptive Behaviour Dementia Questionnaire (ABDQ): Screening questionnaire for dementia in Alzheimer's disease in adults with Down syndrome. *Research in Developmental Disabilities*, 25(4), 385–397. <https://doi.org/10.1016/j.ridd.2003.12.002>
- Rand, S., Malley, J., Forder, J., & Netten, A. (2015). Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer). *Quality of Life Research*, 24(11), 2601–2614. <https://doi.org/10.1007/s11136-015-1011-x>
- Read, S. T., Wynaden, D., Albrecht, M. A., & Toye, C. (2021). Development of the dementia community attitudes questionnaire. *Dementia*, 20(6), 1940–1957. <https://doi.org/10.1177/1471301220977649>

- Ready, R. E., Ott, B. R., Grace, J., & Fernandez, I. (2002). The Cornell-Brown Scale for Quality of Life in dementia. *Alzheimer Disease and Associated Disorders*, 16(2), 109–115.  
<https://doi.org/10.1097/00002093-200204000-00008> ↗
- Sadak, T., Korpak, A., & Borson, S. (2015). Measuring caregiver activation for health care: Validation of PBH-LCI:D. *Geriatric Nursing*, 36(4), 284–292.  
<https://doi.org/10.1016/j.gerinurse.2015.03.003> ↗
- Sadak, T., Korpak, A., Wright, J. D., Lee, M. K., Noel, M., Buckwalter, K., & Borson, S. (2017). Psychometric evaluation of Kingston Caregiver Stress Scale. *Clinical Gerontologist*, 40(4), 268–280. <https://doi.org/10.1080/07317115.2017.1313349> ↗
- Schepers, A., Orrell, M., Shanahan, N., & Spector, A. (2012). Sense of Competence in Dementia Care Staff (SCIDS) scale: Development, reliability, and validity. *International Psychogeriatrics*, 24(7), 1153–1162.  
<https://doi.org/10.1017/S104161021100247X> ↗
- Silverman, W., Krinsky-McHale, S., Lai, F., Rosas, H. D., Hom, C., Doran, E., Pulsifer, M., Lott, I., Schupf, N., The Alzheimer's Disease in Down Syndrome (ADDS) Consortium. (2021). Evaluation of the National Task Group-Early Detection Screen for Dementia: Sensitivity to 'mild cognitive impairment' in adults with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 34(3), 905–915.  
<https://doi.org/10.1111/jar.12849> ↗
- Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R. H., Foley, B., Smith, P., ... Knapp, M. (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychological Medicine*, 37(5), 737–746.
- Stoner, C. R., Orrell, M., & Spector, A. (2018). Psychometric properties and factor analysis of the Engagement and Independence in Dementia Questionnaire (EID-Q). *Dementia and Geriatric Cognitive Disorders*, 46(3–4), 119–127.  
<https://doi.org/10.1159/000488484> ↗
- Stoner, C. R., Orrell, M., & Spector, A. (2019). The psychometric properties of the control, autonomy, self-realisation and pleasure scale (CASP-19) for older adults with dementia. *Aging & Mental Health*, 23(5), 643–649.  
<https://doi.org/10.1080/13607863.2018.1428940> ↗
- Tariq, S., Tumosa, N., Chibnall, J., Perry III, H., & Morley, J. (2006). Comparison of the Saint Louis University mental status examination and the mini-mental state examination for detecting dementia and mild neurocognitive disorder—a pilot study. *American Journal of Geriatric Psychiatry*, 14(11), 900–910.  
<https://doi.org/10.1097/01.jgp.0000221510.33817.86> ↗



## References

- Tarlow, B., Wisniewski, S., Belle, S., Rubert, M., Ory, M., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging, 26*(4), 429–453. <https://doi.org/10.1177/0164027504264493>
- Tebb, S. S., Berg-Weger, M., & Rubio, D. M. (2013). The Caregiver Well-Being Scale: Developing a short-form rapid assessment instrument. *Health & Social Work, 38*(4), 222–230. <https://doi.org/10.1093/hsw/hlt019>
- Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., ... Stewart-Brown, S. (2007). The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes, 5*, 63. <https://doi.org/10.1186/1477-7525-5-63>
- Tocchi, C., Dixon, J., Naylor, M., Sangchoon, J., & McCorkle, R. (2014). Development of a frailty index measure for older adults: The Frailty Index for Elders. *Journal of Nursing Measurement, 22*(2), 223–240. <https://doi.org/10.1891/1061-3749.22.2.223>
- Topp, C. W., Østergaard, S. D., Søndergaard, S., & Bech, P. (2015). The WHO-5 Well-Being Index: A systematic review of the literature. *Psychotherapy and Psychosomatics, 84*, 167–176. <https://doi.org/10.1159/000376585>
- Toye, C., Lester, L., Popescu, A., McInerney, F., Andrews, S., & Robinson, A. L. (2014). Dementia Knowledge Assessment Tool Version Two: Development of a tool to inform preparation for care planning and delivery in families and care staff. *Dementia, 13*(2), 248–256. <https://doi.org/10.1177/1471301212471960>
- Weaver, E., & Samia, L. (2016). *Dementia Crisis to Thriving Scale*. Southern Maine Agency on Aging.
- Weiner, M., Martin-Cook, K., Svetlik, D., Saine, K., Foster, B., & Fontaine, C. (2000). The Quality of Life in Late-stage Dementia (QUALID) scale. *Journal of the American Medical Directors Association, 1*(3), 114–116.
- Wiese, L. K., Williams, C. L., Tappen, R. M., & Newman, D. (2020). An updated measure for investigating basic knowledge of Alzheimer's disease in underserved rural settings. *Aging & Mental Health, 24*(8), 1348–1355. <https://doi.org/10.1080/13607863.2019.1584880>
- Wisniewski, S., Belle, S. H., Coon, D., Marcus, S., Ory, M., Burgio, L., ... Schulz, R. (2003). The Resources for Enhancing Alzheimer's Caregiver Health (REACH) project design and baseline characteristics. *Psychology and Aging, 18*(3), 375–384. <https://doi.org/10.1037/0882-7974.18.3.375>

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- Yamashita, K. Y., Deol, E. S., Elliott, S. J., Morley, J. E., & Malmstrom, T. K. (2022). Validation of the Saint Louis University Quality of Life Questionnaire in Older Adults with Alzheimer's Disease. *Journal of Prevention of Alzheimer's Disease*, 9(4), 809–812. <https://doi.org/10.14283/jpad.2022.60> ↗
- Yesavage, J., Brink, T., Rose, T., Lum, O., Huang, V., Adey, M., & Leirer, V. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17(1), 37–49. [https://doi.org/10.1016/0022-3956\(82\)90033-4](https://doi.org/10.1016/0022-3956(82)90033-4) ↗
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30–41. [https://doi.org/10.1207/s15327752jpa5201\\_2](https://doi.org/10.1207/s15327752jpa5201_2) ↗