

Introduction to Caregiver Assessment Tool Grid

- **The Michigan Dementia Coalition does not endorse any particular assessment tool.**
- **A trained professional should administer these tools (including self-reports), and work with family caregivers, guiding them toward a strategic plan and appropriate supports and services.**

The MDC's Caregiver Support Workgroup issued the report, "Research-Based Recommendations for Effective Caregiver Interventions" in 2008 (www.dementiacoalition.org). The first of four recommendations is: Conduct assessments. "An accurate and systematic information gathering process is necessary to identify caregiver needs, resources and strengths, to determine appropriate goals, and to match interventions that are most likely to assist the caregiver in achieving the desired goals. In addition, a periodic follow-up assessment should be made to monitor the fluctuating caregiver needs as the care situation changes over time. The caregiver assessment is also instrumental in identifying appropriate system changes that can improve home and community-based health care delivery."

The following Caregiver Assessment* Tool Grid identifies researched and well-used tools to identify stress, depression, burden, and other attributes for family caregivers of persons with dementia. The information is provided as a resource for organizations considering implementing caregiver assessment as part of their service provision. It is not an exhaustive list nor does the Michigan Dementia Coalition (MDC) recommend or endorse these instruments. Tools not easily accessed are not included. Specific dementias with varying issues may require other caregiver assessment tools. This list will be periodically reviewed and updated.

It is recommended that those who administer these tools (including follow-up with self-report tools) are trained as care managers or counselors to effectively work with family members to guide them toward appropriate supports, services, education, and other interventions. A care plan, strategies, and identification of available resources should be developed collaboratively with the caregiver and professional. Most caregiver assessments are carried out when a care recipient first enters the service delivery system, when a health care provider identifies a patient caregiver, or when the family caregiver contacts an agency for information and assistance, although they may be more open to an assessment of their own needs once an immediate crisis has passed.

Given limited funding and scarcity of resources for family caregivers of person with dementia, the correct use of assessment tools, such as those listed in this grid, can promote the provision of efficient, cost-effective and targeted services and interventions to support caregivers.

Caregiver Support Workgroup, Michigan Dementia Coalition, June 2009

**Caregiver Assessment: "A systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver's perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver's own health and well-being." From "Caregivers Count Too!" Family Caregiver Alliance, National Center on Caregiving, June 2006.*

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

MDC	Title and Acronym	Developed by	Summary	What does it assess, domains	Evidenced Based (sites, article /research)	Tool Information	Who conducts, qualifications required	Access, Public Domain, Source
1	Alzheimer's Association Caregiver Stress Check	Alzheimer's Assn	Simple yes/no questions, with click link to available resources for each concern.	Identifies areas of CG worry and anxiety		8	Self-report	www.alz.org/stresscheck
2	AMA Caregiver Self-Assessment Tool "How Are You?"	American Medical Association	Helps CGs analyze their own behavior and health risks and, with their physician's help or care mgr guidance, make decisions regarding need for supportive services and referrals. Provides next step suggestions related to scoring.	Emotional and physical distress	Levine C (2003 December) *See chart	18: 16 yes/no 2 global scale items	Self-report or with physician/case manager: suggested that physicians use the tool for CGs in waiting rooms	Google: AMA CG Assessment Tool http://www.ama-assn.org/ama/upload/mm/36/caregivertooleng.pdf
3	Appraisal of Caregiving Scale (ACS)	Marilyn Oberst	CGs perception of intensity of 5 dimensions, with focus on areas of potential stress for CGs: caregiving tasks, relationships and interpersonal support, lifestyle, emotional and physical health, personal impact.	Harm/loss, threat, challenge, benefit, benign	Oberst MT (1989) Carey P (1991) *See chart	72 ranging from "very untrue" to "very true"	Interviewer or Self-report	Permission to use granted on receipt of written agreement to make raw data available to the copyright holder for purposes of continued psychometric testing, and small fee to cover reproduction and mailing expenses. Authorized users will receive periodic updates.
4	California Caregiver Resource Centers Uniform Assessment Tool	Administered by California Dept. of Mental Health for state-funded CG support programs	Assesses support/living situation, functional level of care receiver, memory and behavioral problems, health, Zarit Interview, other caregiving issues and placement, information needs (disease/disorder, resources), and CES-D Depression Scale. Finalizes in Plan of Action by staff.	Needs/situations of family CGs to aid in care planning and service development	Family CGSs Alliance *See chart	103: 55 plus Zarit, CES-D, and demographics 1.5 hours to administer	Case Manager	www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1717

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

MDC	Title and Acronym	Developed by	Summary	What does it assess, domains	Evidenced Based (sites, article /research)	Tool Information	Who conducts, qualifications required	Access, Public Domain, Source
5	C.A.R.E. (Caregivers' Aspirations, Realities & Expectations)	Guberman N, Keefe J, Fancey P, Barylak L, 2001	Enables a CG to discuss the various aspects of his/her situation, identify specific services needed to support the CG, provide assessor with an understanding of the CGs daily experiences, understand the conditions, context and consequences of caregiving situations. Sections describe CG work and support received: physical/nursing care, household, supervising, coordination, relationship to formal services, housing, transportation, juggling responsibilities, financial costs, personal health, family relationships and planning issues.	Key areas of concerns of CG support needs, physical and nursing care, informal and formal support. To help understand caregivers' aspirations, realities, and expectations.	Guberman N (2001) Guberman N (2003) *See chart	Approx. 65 major items	Interviewer/assessor, home care practitioners. Summary Section to be filled out by assessor alone following the interview	www.msvu.ca/Family&GerontologyCaregiverAssessmentTool/Instruments.asp Users are required to complete a user Agreement Form available from the authors or online at www.msvu.ca/Family&Gerontology/Project .
6	Caregiver Problem Checklist & Strain Scale	C.J. Gilleard	Problem Checklist: assessment of problems experienced by CG of patients with dementia. Strain scale: assessment of strain. Items include ADLs (i.e. needs help with dressing) and such behaviors as repeating questions and careless about own appearance.	Checklist of problems with ADL's, IADL's, Behaviors, and others, with indication of corresponding level of strain for each	Gilleard CJ (1984) Croom Helm (1982) *See chart	34 items on 3-pt scale: not present, occasionally occurring, frequently occurring; if occasionally or frequently occurring, 3-pt rating scale: no problem, some problem, great problem Scale includes 12 items Takes 20 minutes to administer	Interviewer	http://books.google.com Google by the author
7a	Caregiving Self-Efficacy Scale (CSS)	CG Self-Efficacy (Zeiss et al, 1999)	<i>Need help with which Scale?</i> 14-item interview format measure of CGs self-efficacy (i.e. judgments regarding one's ability to perform effectively in certain situations). Measure is comprised of two sub-scales: CG Self-care Self-efficacy and CG problem-solving, self-efficacy. Respondents rate their level of confidence for each item on a scale of 0-100.	CG self-perception of abilities, effectiveness, problem solving				

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

MDC	Title and Acronym	Developed by	Summary	What does it assess, domains	Evidenced Based (sites, article /research)	Tool Information	Who conducts, qualifications required	Access, Public Domain, Source
7b	Caregiving Self-Efficacy Scale (CSS)	Antonette M. Zeiss et al (1999) Revised 2002: Steffen, McKibbin, Zeiss, Gallagher-Thompson, Bandura	Measures 3 domains of caregiving self-efficacy (i.e. judgments regarding one's ability to perform effectively in certain situations; a person's belief about her/his ability to organize and execute courses of action to manage given situations): obtaining respite, responding to disruptive patient behaviors, and controlling upsetting thoughts. Self-efficacy beliefs determine whether coping behaviors will be initiated, how much effort will be expended, and how long effort will be sustained in face of obstacles and aversive experiences, and affect vulnerability to emotional distress and depression.	CG self-perception of abilities, effectiveness, problem solving in handling respite, behaviors, thoughts	Zeiss AM (1999) Steffen A (Jan 2002) *See chart	15 items; 5 items in each of 3 domains How confident you are that you can keep up your own activities and also respond to caregiving situations.	Of use to clinicians in selecting intervention strategies for CGs. Interviewer reads items which cover actions and thoughts that could come up for you as a CG. On scale 0-100, how confident you are that you could do each item. Can't do at all (0) to Certain Can Do (100)	Reproduction prohibited without permission. www.des.emory.edu/mfp/Bandura2003JG.pdf Steffen, public domain: http://psychsoc.gerontologyjournals.org/cgi/content/full/57/1/P74#TA1
8	Center for Epidemiology Studies Depression Scale (CES-D)	Lenore Radloff	Screening test for depression, helping an individual determine his/her depression quotient; measures depressive feelings and behaviors over last week.	Depression	Radloff LS (1977) Radloff LS (1986) *See chart	20: 4-point rating from Rarely to All of the time 5 minutes to administer	Self-Report	http://patienteducation.stanford.edu/research/cesd.pdf www.chcr.brown.edu/pcoc/cesdscale.pdf
9	Geriatric Depression Scale (GDS)	Yesavage JL, et al.	Identifies and rates of depressive symptomatology in elderly people. Useful screening tool in the clinical setting to facilitate assessment of depression in older adults especially when baseline scores are compared with subsequent scores over time. Not a substitute for a diagnostic interview by mental health professionals.	Depression	Yesavage JL (1983) Sheikh JI (1986) *See chart	30: 15 Yes/No questions in reference to how they felt over the past week; scoring not depressed, mild depression; severe depression. The short form is more easily used by physically ill and mildly to moderately demented patients who have short attention spans and/or feel easily fatigued. 5-10 minutes to administer	Self-report	Google: Geriatric Depression Scale http://www.stanford.edu/~yesavage/GDS.html

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

MDC	Title and Acronym	Developed by	Summary	What does it assess, domains	Evidenced Based (sites, article /research)	Tool Information	Who conducts, qualifications required	Access, Public Domain, Source
10	Risk Appraisal Measure	Czaja, et al (Burgio)	Measure assesses six domains linked to caregiver risk and amenable to intervention: depression, burden, self-care and health behaviors, social support, safety, and patient problem behaviors: suggested intervention strategies for each domain; uses multidimensional scale; can be used in research, clinical and community settings to guide, prioritize and target needed areas of support for caregivers.	Well-being and identifies risk area and needed areas of support	Czaja, et al., (2009) Belle SH, Burgio L, Burns R et al. (2006) *See chart	16 on a 4, 5, 6 or 7 point range; 5-7 minutes	Researchers, clinicians and service providers	
11	MM Caregiver Grief Inventory	Thomas Meuser and Samuel Marwit	Inventory is designed to measure the grief experience of current family CGs of persons living with progressive dementia. Scoring indicates Personal Sacrifice Burden, Heartfelt Sadness and Longing, Worry & Felt Isolation and Total Grief Level. Scores also indicate need for formal intervention or support assistance to enhance coping, denial or downplaying of distress, positive adaptation and common reactions.	Anticipatory grief experience	Marwit SJ & Meuser TM (2002) Vitaliano PP (1991) *See chart	50	Self-Report	http://gerontologist.gerontologyjournals.org/cgi/reprint/42/6/751
12	Pearlin Caregivers' Stress Scales	L.I. Pearlin	Based on a conceptual model of Alzheimer's CGs stress. Scale topics include primary stressors (cognitive status, problematic behavior, overload, relational deprivation), secondary role strains (family conflict, job-caregiving conflict, economic strains), secondary intrapsychic strains (role captivity, loss of self, caregiving competence, personal gain) and mediators (management of situation, management of meaning, management of distress, expressive support).	Stress, family roles, caregiving competence	Pearlin LI (1990) Pearlin LI (1994) *See chart	15, 3-point to 5-point scales		Leonard Pearlin, Ph.D. Professor, University of Maryland Office: 4101 Art-Sociology Building Phone: 301 405-7706 Email: lpearlin@socy.umd.edu
13	Perceived Change Index (Gitlin)	Gitlin	Revised Version forthcoming, Contact Dr. Laura Gitlin, laura.gitlin@jefferson.edu		Data pending, to be released			laura.gitlin@jefferson.edu

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

MDC	Title and Acronym	Developed by	Summary	What does it assess, domains	Evidenced Based (sites, article /research)	Tool Information	Who conducts, qualifications required	Access, Public Domain, Source
14	Positive CG Scale Or Picot Caregiver Rewards Scale	Barbara Tarlow Sandra Picot	<i>Positive Aspects of Caregiver; Contributions of the REACH project, Tarlow 2004.</i> Assesses rewards of caregiving. Respondents rate the degree to which items describe positive consequences of their caregiving on a 5-point Likert scale (ranging from "not at all" to "a great deal").	Positive aspects and rewards of caregiving Rewards of caregiving in adults	Tarlow BJ (2004) *See chart Picot SJ (1997) *See chart	11 questions: how much agree/disagree. 24		Need to pay SAGE publications for access.
15	Rosalyn Carter Institute Family Caregiver Assessment RCI-FCA	Rosalyn Carter Institute	The instrument is specifically designed to assess the psycho-social needs of family caregivers.	Part 1-Profile of family CG, CR and caregiving situation. Part 2 – family and community supports.		35, multi-part questions; administration time 40-65 minutes	Professionals providing services or assistance to families in which there are person with serious illnesses or disabilities	http://www.rosalynncarter.org/UserFiles/File/RCI_FCA.pdf
16	T-CARE Tailored Caregiver Assessment & Referral process	Rhonda J.V. Montgomery	Assesses CGs needs and creates individualized care plans that will maximize benefits for families throughout their caregiving journey while allocating organizational resources in an efficient manner. Grounded in CG Identity Theory, describing caregiving as a systematic process of identity change in which the initial familial relationship gives way to a relationship characterized by caregiving. This change in identity influences the type and level of stress or burden for the CG and serves as a guide for effectively targeting services and appropriate CG support strategies. A central feature of the T-CARE protocol is a set of maps/algorithms that guide care managers through a decision process.	Distress and support strategies	Data pending, to be released	Six-step CG assessment and referral process 2-4 hours for initial time to administer	Care Managers trained in T-CARE protocol	Not yet ready for dissemination. Pilot organization training; rm@uwm.edu Department of Social Work 1157A Enderis Hall 414-229-3289

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

MDC	Title and Acronym	Developed by	Summary	What does it assess, domains	Evidenced Based (sites, article /research)	Tool Information	Who conducts, qualifications required	Access, Public Domain, Source
17	Ways of Coping Checklist	Original: Folkman and Lazarus (1980) Revised 1985: P.P.Vitaliano, et al	Assesses coping strategies in CGs of patients with Alzheimer's disease. A measure of an individual's ability to cope. Contains wide range of thoughts and acts that people use to deal with internal and/or external demands of specific stressful encounters. 5 domains of problem-focused, seeks social support, blamed self, wishful thinking, avoidance.	Individual's ability to cope based on Lazarus's transactional model of stress.	Vitaliano PP (1985) Folkman S (1980) *See chart	Revised: 42 items: 30 minutes to administer	Self-Report; rating by trained psychologist	Google the author http://books.google.com/books 1985 version in public domain; 1988 Consulting Psychologist Press modification is copyrighted and needs permission: http://www.mindgarden.com
18	Zarit Burden Interview (Burden Interview)	Steven Zarit	Measures subjective burden, distress and perceptions of social, physical/health, financial, and emotional burden, and relationship with care receiver. Indicates the CGs emotional state and to assist in developing a plan of care for the CG. 5-point scale from never to nearly always; Sample: Do you feel angry when you are around your relative? Do you feel that your relative asks for more help than s/he needs?	Burden	Zarit SH (1980) *See chart Bédard et al., 2001	22 12, Short-version 25 minutes to administer	Self-Report during an assessment interview	http://memoryclinic.uchc.edu/siteindex/site.html http://gerontologist.gerontologyjournals.org/cgi/content/abstract/41/5/652
19	SF-36 SF-36® is a registered trademark of the Medical Outcomes Trust.	New England Medical Center Hospitals (J. E. Ware, Jr., Principal Investigator).	Health review – general, not specific to caregivers. It yields an 8-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index. It is a generic measure, as opposed to one that targets a specific age, disease, or treatment group. Accordingly, the SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases, and in differentiating the health benefits produced by a wide range of different treatments.	Mental and Physical Health	New England Medical Center Hospitals *See chart	36	Self report	All use of QualityMetric health surveys requires a signed license agreement. http://www.qualitymetric.com/DefaultPermissions/RequestInformation/tabid/233/Default.aspx/

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

Caregiver Assessment Tools Grid

- **The Michigan Dementia Coalition does not endorse any particular assessment tool.**
- **A trained professional should administer these tools (including self-reports), and work with family caregivers to guide them toward a strategic plan and appropriate supports and services.**
- **The Michigan Dementia Coalition recognizes that there are other caregiver assessments being developed. Updates and new information will be added as they become available.**

**Evidenced Based
(sites, article/research)**

1..	No info
2.	Levine,C.,Depression in Caregivers of Patients with Dementia. Jo of Gen Internal Medicine. 2003 December, 18(12): 1058-1059.
3.	Oberst, MT, Thomas S, Gass K, & Ward, S (1989). Caregiving demands and appraisal of stress among family caregivers. Cancer Nursing, 12, 209-215. Carey P, Oberst, MT, McCubbin M, & Hughes S (1991).
4.	Family CGs Alliance; Examples of CG Assessment Tools; www.caregiver.org
5.	Guberman, N. Keefe, J., Nahmiash, Barylake, L. (2001) Development of Screening and Assessment Tools for Family Caregivers. Ottawa, Canada: Health Transition Fund of Health Canada. Guberman, Nicholas, Nolan, Rembicki, Lundh, Keefe (2003). Impacts on practitioners of using research-based carer assessment tools: Experiences from the UK, Canada and Sweden. Health and Social Care in the Community, 11(4), 345-355

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

6.	Gilleard, CJ (1984) Living with dementia: community care of the elderly mental infirm. Beckenham: Croom Helm. Gilleard CJ, Watt G (1982) The impact of psychogeriatric day care on the primary supporter of the elderly mentally infirm. In Taylor R, Gilmore A, eds. Current trends in British Gerontology. Aldershot: Gower Publishing, 139-47.
7a.	No info
7b.	Zeiss AM, Gallagher-Thompson D, Lovett S, Rose J, McKibbin C, 1999. Self-efficacy as a mediator of caregiver coping: development and testing of an assessment model. Journal of Clinical Geropsychology, 5, 221-230. Steffen A, McKibbin C, Zeiss AM, Gallagher-Thompson D, Bandura A, The Revised scale of caregiving self-efficacy: Reliability and validity studies. The Journals of Gerontology, Jan 2002, 57B, 1; Research Library, p. P74.
8.	Radloff LS (1977) The CES-D Scale: A self-report depression scale for research in the general population. Applied Psychological Measurement 1: 385-401. L.S. Radloff, Teri L. 1986, Clinical Gerontologist 5:119-37
9.	Yesavage JL, Brink TL, Rose TL, Lum O, Huang V, Adey M, Leirer O, 1983, Journal of Psychiatric Research 17:37-49 Sheikh JI, Yesavage JA: Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. Clinical Gerontology : A Guide to Assessment and Intervention 165-173, NY: The Haworth Press, 1986
10.	Czaja, et al., "Development of the Risk Appraisal Measure: A Brief Screen to Identify Risk Areas and Guide Interventions for Dementia Caregivers," Journal of the American Geriatrics Society, 57: 1064-1072, 2009. Belle SH, Burgio L, Burns R et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups, Ann Intern Med 2006; 145:727-738.
11.	Marwit, SJ & Meuser, TM (2002) Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons with Alzheimer's Disease. The Gerontologist. 42(6), 751-765. Meuser, TM & Marwit, SJ (2001) A comprehensive, stage-sensitive model of grief in dementia caregiving. The Gerontologist. 41(5), 658-770. Vitaliano PP, Russo J, Young HM et al. The screen for caregiver burden. The Gerontologist. 1991; 31, 1: 76-83.
12.	Pearlin LI, Mullan JT, Semple SH and Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. The Gerontologist. 1990; 30, 5:583-594. Pearlin, L. I., (1994). Conceptual strategies for the study of caregiver stress. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.), Stress effects on family caregivers of Alzheimer's patients: Research and interventions (pp. 3–21). New York: Springer.
13.	No info- data pending – to be released
14.	<i>Positive Aspects of Caregiver; Contributions of the REACH project, Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D, Research on Aging. 2004. 26:429-453.</i> <i>Picot SJ, Youngblut J, Zeller R. Development and Testing of a measure of perceived caregiver rewards in adults., J Nrs Meas. Summer 1997; 5(1):33-52.</i>
15.	No info
16.	Data pending and to be released
17.	Vitaliano PP, Russo J, Carr JE, Maiuro RD, Becker J (1985). The Ways of Coping Checklist: revision and psychometric properties. Multivariate Behavioral Research 20: 3-26. Folkman S, Lazarus RS (1980). An analysis of coping in a middle-aged community sample. Journal of Health & Social Behavior, 21: 219-39.

**MICHIGAN DEMENTIA COALITION
CAREGIVER ASSESSMENTS 2009**

18.	Zarit SH, Reever KE, Bach-Peterson J, Relatives of the Impaired elderly: correlations of feelings of burden. 1980, The Gerontologist. 20(6):649-655 Bédard et al.; The Zarit Burden Interview: A New Short Version and Screening Version. 2001, The Gerontologist, 41 (5): 652
19.	Development and validation of the SF-36 Health Survey was supported by a grant from the Henry J. Kaiser Family Foundation to The Health Institute, New England Medical Center Hospitals (J. E. Ware, Jr., Principal Investigator)

Assessment Grid Development Committee: Marci Cameron, MPH; Lorraine Kremer, MSW; Carey Sherman, PhD; Heddie Sumner, RN, BSN