



Caregivers Count Too!

A Toolkit to Help Practitioners Assess
the Needs of Family Caregivers

JUNE 2006



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving



About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Visit www.caregiver.org.

The Robert Wood Johnson Foundation provided the primary financial support for the National Consensus Project *for* Caregiver Assessment. Other funders include the Archstone Foundation and The California Endowment.

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Additional copies of the Toolkit are available at www.caregiver.org

Acknowledgements

The National Center on Caregiving at Family Caregiver Alliance (FCA) is deeply grateful to our funders for their commitment to this important effort and their financial support to make this project possible: The Robert Wood Johnson Foundation, with additional assistance from the Archstone Foundation and The California Endowment.

Sincere appreciation is extended to Cara Goldstein, MSW, at FCA's National Center on Caregiving for drafting this toolkit and to Melania Jusuf at FCA for design work.

Suggested Citation:

Family Caregiver Alliance (2006). *Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers*. San Francisco: Author.

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Preface

*N*ow, more than ever, involving family caregivers is a necessary part of working with older people and adults with disabilities in all practice settings. As our population ages, more people with chronic and disabling conditions are choosing to live at home or in the community, launching their family members and close friends into action as caregivers.

We now know that family caregiving impacts the physical and mental health, finances, career and other family and social relationships of the caregiver. However, few programs offer caregivers an assessment of their own situations to assist them in providing quality care. Restrictions on resources may influence an agency's response to caregiver needs, but much depends on how we view caregivers in general. Are family members seen merely as a resource, or as people with needs and rights of their own?

Achieving a high quality of care for people with chronic or disabling conditions depends on accepting a family-centered perspective. The success of most care plans—from hospital discharge to everyday care in the home—often rests on the shoulders of the family caregiver. If the family caregiver becomes sick or can no longer cope with caregiving tasks, the care recipient suffers. If the strain on a caregiver becomes too great, care in the home may be seriously compromised and nursing home placement may result. Successful care, whether from hospitals, home or community-based settings, depends upon knowing the needs of both the care recipient and the family caregiver.

Establishing caregiver assessment as a basic component of practice across care settings requires a fundamental change in thinking and practice. In September 2005, the Family Caregiver Alliance's (FCA) National Center on Caregiving convened the National Consensus Development Conference for Caregiver Assessment. The conference brought together widely recognized leaders in health and long-term care to advance policy and practice on behalf of family and informal caregivers. Through the consensus development process, conference participants agreed on the central importance of incorporating an assessment of caregiver needs in everyday practice and service delivery settings. These leaders also agreed on basic principles and practice guidelines



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Section 1 Getting Started

What Is the Caregivers Count Too! Toolkit?

Who Should Use This Toolkit?

How Is the Toolkit Organized?

Definitions



Section 1

Getting Started

What Is the Caregivers Count Too! Toolkit?

It's a step-by-step resource filled with practical information and resources. It's designed for program administrators and practitioners to:

1. Sharpen your awareness of family caregivers as an at-risk population in need of assessments to determine their own physical, emotional and financial problems.
2. Give you new knowledge and skills so you can create and put to use a caregiver assessment that works in your particular practice setting.

Who Should Use This Toolkit?

This toolkit is for any professional who works with older people and adults with disabilities, whether service is provided in the home, a hospital, a physician's office, a nursing home or a program in the community. Some specific examples:

- ◆ Social Service Providers (e.g., social workers, care managers, caregiver specialists)
- ◆ Medical and Health Providers (e.g., physicians, nurses, allied health personnel)
- ◆ Program Administrators

How Is the Toolkit Organized?

The toolkit has four main sections:

- ◆ In this section you'll find, besides an introduction, the definitions of terms used throughout the toolkit.
- ◆ The second section focuses on the key role of family caregivers—who they are, what they do, and why knowing their needs is important. A list of additional resources we have found useful and sources used for statistics are also provided at the end of the section.

- ◆ The third section provides a set of basic guidelines for conducting caregiver assessment including: recommended areas to cover and questions to include in a caregiver assessment; and answers to the “who, when, where and by whom” questions for implementing the assessment. A list of fundamental principles to guide practitioners in conducting caregiver assessments is also included.
- ◆ The fourth section summarizes the toolkit and provides three appendices with additional information including: six sample caregiver assessment tools; an annotated list of FCA publications relating to caregiver assessment including FCA’s handy publication, *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*; and an annotated bibliography of caregiver assessment materials and journal articles.

DEFINITIONS: WHAT DO WE MEAN BY.....

Activities of Daily Living (ADLs) – everyday tasks related to personal care usually performed for oneself in the course of a normal day, including bathing, dressing, grooming, eating, walking, taking medications, and other personal care activities.

Care Recipient – an adult with a chronic illness or disabling condition or an older person who needs ongoing assistance with everyday tasks to function on a daily basis. The person needing assistance may also require primary and acute medical care or rehabilitation services (occupational, speech and physical therapies).

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.

Caregiver Reassessment – a follow-up interview with the caregiver on a regularly scheduled basis or as needed.

Consumer Direction – a descriptor of service delivery that allows choice and control for people who use services or other supports to help with daily activities.



Family (Informal) Caregiver – any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care.

Formal Caregiver – a provider associated with a formal service system, whether a paid worker or a volunteer.

Home and Community-Based Services (HCBS) – a variety of supportive services delivered in community settings or in a person’s home. These services are designed to help older persons and adults with disabilities remain living at home. Examples of HCBS include personal care with bathing, chore assistance, adult day services, transportation to medical appointments, and home-delivered meals.

Instrumental Activities of Daily Living (IADLs) – activities related to independent living, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

Long-Term Care (LTC) – a combination of medical, nursing, custodial, social, and community services designed to help people who have disabilities or chronic care needs, including dementia. Services may be provided in the person’s home, in the community, in assisted living facilities or in nursing homes.

National Family Caregiver Support Program (NFCSP) – a federal program created by Congress in the 2000 Amendments to the Older Americans Act to recognize the complexities of caring for family members, loved ones and friends. Under the NFCSP, the states use federal funds to offer direct support services to family caregivers of persons age 60 and older, including information to caregivers about available services; assistance to caregivers in gaining access to supportive services; individual counseling, support groups and caregiver training; respite care; and supplemental services (e.g., emergency response systems, home modifications).

Respite Care – provision of short-term relief (respite) from the tasks associated with caregiving. Respite services encompass traditional home-based care, such as hiring an attendant, as well as care provided to the care recipient in out-of-home care settings, such as adult day services and short-term stays in a nursing home or other care facility. Respite can vary in time from part of a day to several weeks.

Screening – a short rapid review with caregivers that identifies those at risk, leading to an opportunity for a full assessment for those wishing to proceed.

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Section 2 Vital & Vulnerable: Family Caregivers

Who Are Family Caregivers?

Why Are Family Caregivers Vital to Health Care
and Long-Term Care Today?

Why Should We Assess the Needs of
Family Caregivers?

Online Resources for More Information

Data Sources for Statistics



Section 2

Vital & Vulnerable: Family Caregivers

Who Are Family Caregivers?

An estimated 44 million Americans age 18 and older provide unpaid assistance and support to older people and adults with disabilities who live in the community. Caregivers are varied in their characteristics, yet research on this increasingly visible group reveals some themes:¹

- ◆ Women outnumber men (about two to one).
- ◆ Most are middle-aged (35-64 years old) and married or living with a partner.
- ◆ Most (83%) are relatives of the person they are caring for, including: daughters/sons, spouses, grandchildren, and siblings.
- ◆ Rates of caregiving vary somewhat by ethnicity. Among the U.S. adult population (18+), about one-fifth (21%) of each of the non-Hispanic white and African-American populations are providing informal care, while a slightly lower percentage of Asian (18%) and Hispanic-Americans (16%) are engaged in caregiving.
- ◆ About one in four (24%) caregivers live with or close to the person they are caring for and about four in ten (42%) are no more than 20 minutes away.
- ◆ About half of caregivers are employed at full-time jobs (48%).
- ◆ The amount of care given on a weekly basis varies widely, from fewer than 8 hours (by nearly half) to more than 40 hours (by 1 in 5).
- ◆ Caregiving goes on for a long time—an average of 4.3 years.

¹ Source: National Alliance for Caregiving & AARP. (2004). *Caregiving in the U.S.* Bethesda, MD: National Alliance for Caregiving.

Why Are Family Caregivers Vital to Health Care and Long-Term Care Today?²

Many people rely on them:

- ◆ Most people (80%) who need LTC supportive services live at home or in community settings, not in institutions.
- ◆ More than 78% of adults who receive LTC at home get all their care from unpaid family and friends.

Family caregivers fill big gaps in health and long-term care:

- ◆ Changes in health care delivery, including shorter hospital stays and limited discharge planning, require family members to provide more difficult, intense care for longer periods of time.
- ◆ Caregivers of people with chronic illnesses or disabilities often have the primary responsibility for carrying out care plans, ensuring that the care recipient's treatment is a success.
- ◆ The shortage of direct care workers in HCBS and nursing home settings leaves many family caregivers without an alternative.

They are saving us money:

- ◆ Unpaid caregiving by family and friends has an estimated national economic value (in 2004) of \$306 billion annually—exceeding combined costs for nursing home care (\$103.2 billion) and home health care (\$36.1 billion).

But... they are not taking care of themselves!

- ◆ One-fourth of women caregivers report health problems as a result of their caregiving activities.
- ◆ Caregivers report higher levels of depressive symptoms and mental health problems than do their noncaregiving peers (20% to 50% report depressive disorders or symptoms).
- ◆ Two-thirds of caregivers report they need help to find care for themselves, to balance work and family responsibilities and to manage emotional and physical stress.

² See *Data Sources for Statistics* on page 2.8 for the statistics in this section.

Why Should We Assess the Needs of Family Caregivers?

Assessment builds caregiver morale and capacity:

- ◆ Caregivers who have their needs assessed feel acknowledged, valued, and better understood by practitioners.
- ◆ Caregivers gain a better grasp of their role and the abilities required to carry out tasks.
- ◆ If the physical, emotional and financial strains on family caregivers become too great, care in the home may be seriously jeopardized.

It's the key to care planning:

- ◆ Identifying service needs and unresolved problems is fundamental to a plan that supports and strengthens the family as a whole, where most care is given and received.
- ◆ Caregiver strain and health risks can impede the caregiver's ability to provide care, lead to higher health care costs, and affect the quality of life for caregivers and those for whom they care.
- ◆ The well-being of the family caregiver is often key to the care recipient's getting the help needed at home or in the community—rather than placement in a nursing home.

It opens doors for the caregiver and the care recipient:

- ◆ Assessment can establish eligibility for useful services, supporting the caregiver and the care recipient.
- ◆ Knowing caregiver needs and preferences triggers timely referrals.

It's a way to monitor program effectiveness and to inform policy:

- ◆ Information from caregivers reveals what works and what does not.
- ◆ Caregiver feedback helps assure quality of care.
- ◆ Patterns seen across caregivers and over time reveal gaps and priorities for new programs and better policies.

Caregivers Count Too!

Commonly held misperceptions about including family members in the assessment process stand in the way of recognizing, understanding and meeting caregivers' needs. Some of these are:

MYTH	REALITY
1. The caregiver isn't my client. Besides, this would be an intrusion into the caregiver's time and privacy.	Illness is a "family affair." Most caregivers appreciate the assessment process and view it as an opportunity to express their own needs and have their situation taken seriously.
2. If I talk to family members, I won't have time to complete my other responsibilities.	Assessments need not be lengthy or duplicate information already collected. Done correctly, the assessment process results in a more efficient use of time. Caregivers may provide significant insight into the patient's situation, identify important issues that might have been overlooked and improve the focus of information collected.
3. I won't have the answers or resources to deal with a caregiver's additional issues.	Avoiding or excluding caregiver issues leads to a bigger problem. It is possible to work creatively with caregivers to tailor use of limited resources, the most important thing is that the caregiver feels listened to and acknowledged.
4. The assessment process will interfere with the natural flow of the clinical process and get in the way of my ability to develop a trusting rapport.	An assessment tool is a framework to guide the conversation and assure that vital information is collected consistently. However, the clinician does not have to rigidly follow the order and wording, or ask a question that does not apply.
5. Assessments are only used for research purposes and don't help a person who needs services.	When linked to a care plan with service interventions, assessment can point to particular services; reassessment can track progress and identify needed changes to the interventions.

Online Resources for More Information

Family Caregiver Alliance National Center on Caregiving

Offers comprehensive caregiving information and advice, fact sheets, reports and studies, discussion groups and newsletters for caregivers, practitioners, policymakers and researchers. In addition, a state-by-state resource guide offers a searchable database of publicly-funded caregiver support programs.

Phone: 800-445-8106

Website: www.caregiver.org

Family Caregiver Alliance’s National Center on Caregiving offers a free e-newsletter, *Caregiving PolicyDigest*. This newsletter is delivered twice a month and includes briefings on key legislation, news on innovative programs, and the latest information on caregiving and long-term care policy at national and state levels.

Subscribe at: www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=836

AARP

A consumer-oriented site offering caregivers information about general topics in caregiving, including “caring for parents” and “finding help.”

Phone: 888-687-2277

Website: www.aarp.org/families/caregiving

Administration on Aging National Family Caregiver Support Program (NFCSP)

Offers the “Caregiver Resource Room,” where families, caregivers, and professionals can find information about the National Family Caregiver Support Program, including where to turn for support and assistance, and services for caregivers.

Phone: 202-619-0724

Website: www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp

American Society on Aging C.A.R.E-Pro

Caregiving Awareness through Resources and Education for Professionals (CARE-Pro) provides training to increase the skills and knowledge of nurses, occupational therapists and social workers who provide needed services to family caregivers through e-learning. A free CD-ROM consisting of seven modules focusing on family caregiving intended to provide education and discussion can be ordered online.

Website: www.asaging.org/caregiving_resources.cfm

ARCH National Respite Network

Provides information on respite programs, policy and other initiatives (such as trainings and conferences) around the country. The site also includes a respite locator service to help you find your nearest providers.

Website: www.archrespite.org/index.htm

Caring Today Magazine

Provides information, support and guidance for family and professional caregivers. The website includes tips, guides and personal stories about caregiver health, family, financial, legal and medical issues.

Website: www.caringtoday.com

Johnson & Johnson Strength for Caring

This website for caregivers contains six main sections: caregiver manual, community, health conditions, daily care, housing and money and insurance.

Website: www.strengthforcaring.com

Mather Lifeways Powerful Tools for Caregivers

The Mather LifeWays Institute on Aging offers fee-based online and in-person education programs that enhance the knowledge and self-care skills of family caregivers.

Phone: 888-722-6468

Website: http://matherlifeways.com/re_powerfultools.asp

MetLife Mature Market Institute Since You Care Guides

Since You Care® are a series of guides which provide practical suggestions and useful tools on a variety of specific care-related subjects.

Website: www.metlife.com/Applications/Corporate/WPS/CDA/PageGenerator/0,1674,P8900,00.html

National Alliance for Caregiving

Includes information on caregiving research studies and policy analyses and links to the Family Care Resource Connection, which includes reviews and ratings of books, videos, websites, and other resources on family caregiving issues.

Website: www.caregiving.org

NAC also hosts the Caregiving listserv, which is a source of information on events, research, programs and more. List subscribers are professionals with an interest in family caregiving issues.

Subscribe at: <http://mailman.listserve.com/listmanager/listinfo/caregiving>

National Family Caregivers Association

Consumer-oriented site that supports family caregivers and offers education, information and resources.

Phone: 800-896-3650

Website: www.nfcacares.org

National Institute on Aging

Offers free publications on caregiving subjects including doctor/patient communication and a long-distance caregiver guide.

Website: www.niapublications.org/shopdisplayproducts.asp?id=29&cat=Caregiving

Rosalyn Carter Institute for Caregiving

Includes information on programs, education and training, a caregiver community forum, publications and current events in caregiving.

Website: <http://rci.gsw.edu>

Data Sources for Statistics

Agency for Healthcare Research and Quality. (2000). *Long-term Care Users Range in Age and Most do not Live in Nursing Homes: Research Alert*. Rockville, MD: Author. Available online at: www.ahrq.gov/research/nov00/1100RA19.htm

Alexih, L. M. B., S. Zeruld, and B. Olearczyl. (2001). *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. [National Family Caregiver Support Program: Selected Issue Briefs.] Falls Church, VA: The Lewin Group. Available online at: www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/background/program_issues/AlexihMonograph.pdf

Arno, P. S. (2006). *The Economic Value of Informal Caregiving: 2004*. Presented January 25-27 at the Care Coordination & the Caregiver Forum, Bethesda, MD: Department of Veteran Affairs, NIH. Available online at: www.va.gov/oc/Conferences/caregiverforum/Docs/Arno-Handout.pdf

Bass, D. (2002). *Content and Implementation of a Caregiver Assessment*. [Issue Brief]. Washington, D.C.: Administration on Aging. Available online at: www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/background/program_issues/Fin-Bass.pdf

Feinberg, L.F (2004). *The State of the Art: Caregiver Assessment in Practice Settings*. San Francisco, CA: Family Caregiver Alliance. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/op_2002_state_of_the_art.pdf

Komisar, H. & L. Thompson. (2004). *Who Pays for Long-term Care?* Fact Sheet, Long-Term Care Financing Project. Washington, DC: Georgetown University Press. Available online at: <http://ltc.georgetown.edu/pdfs/whopays2004.pdf>

National Alliance for Caregiving & AARP. *Caregiving in the U.S.* Bethesda, MD: National Alliance for Caregiving, 2004. Available online at: www.caregiving.org/data/04finalreport.pdf

Older Women's League. (2003). *Women and Long-term Care*. Retrieved from: www.owlnational.org

Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35:771-791.
Available online at: <http://intl-gerontologist.gerontologyjournals.org/cgi/content/abstract/35/6/771>

Spector, W. D., Fleishman, J., Pezzin, L. & Spillman, B. (2000). *The Characteristics of Long-Term Care Users*. AHRQ Publication No. 00-0049. Rockville: Agency for Healthcare Research and Policy.
Available online at: www.ahrq.gov/RESEARCH/lcusers/

The Henry J. Kaiser Family Foundation, Harvard School of Public Health, United Hospital Fund of New York, and Visiting Nurse Service of New York. (2002). *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*. Menlo Park: Kaiser Family Foundation.
Available online at: www.kff.org/kaiserpolls/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13990

Thompson, L. (2004). *Long-term Care: Support for Family Caregivers* [Issue Brief]. Washington, DC: Long-Term Care Financing Project, Georgetown University.
Available online at: <http://ltc.georgetown.edu/pdfs/caregivers.pdf>

U.S. Department of Health and Human Services and Assistant Secretary for Planning and Evaluation. (2003). *The Future Supply of Long-term Care Workers in Relation to the Aging Baby Boom Generation*. Report to Congress. Washington, DC: Author.
Available online at: <http://aspe.os.dhhs.gov/daltcp/reports/lcwork.htm>

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Section 3 The Nuts & Bolts of Caregiver Assessment

Getting Started

What Should a Family Caregiver Assessment Include?

Who Should Be Assessed?

Who Should Conduct a Family Caregiver Assessment?

When Should a Family Caregiver Assessment Happen?

Where Should a Family Caregiver Assessment Take Place?

Fundamental Principles for Caregiver Assessment



Section 3

The Nuts & Bolts of Caregiver Assessment

So you agree that caregivers are vital and vulnerable and that knowing their needs and strengths is important to keep them on the job, but what do you DO about that? How do you introduce caregiver assessment into *your* practice setting?

Getting Started: Focus on Your Program

Carrie Smith is a Family Caregiver Support Program Specialist at a Michigan Area Agency on Aging. She's interested in assessing the needs of the caregivers she works with and has heard that some assessment instruments have been developed by others. How should she get started?

Before she chooses—or creates—an instrument, she needs to think about her program and how she will use assessment in it. There is no single “right” way to approach caregiver assessment for all care settings and situations.

Some questions Carrie needs to consider are:

1. Does her program serve all types of caregivers, or just those for care recipients with a specific type of diagnosis (for example, Alzheimer's disease or other forms of dementia)?
2. What are her program's goals or intended outcomes?
3. How will she use the assessment information? For clinical purposes and care planning only? For quality assurance? Outcomes analysis? Or policy development?

Once you have your program purpose in clear focus and know how you hope to use the information gathered by the caregiver assessment process, you are ready to tackle the details. It is important to keep in mind that assessment is not an end point. Rather, it should empower family caregivers to make informed decisions and link caregivers with community services.

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The “nuts & bolts” of caregiver assessment are contained in five questions. We’ll take you through them, one by one. The questions are:

- ◆ What Should a Family Caregiver Assessment Include?
- ◆ Who Should Be Assessed?
- ◆ Who Should Conduct Family Caregiver Assessments?
- ◆ When Should Family Caregiver Assessment Happen?
- ◆ Where Should Family Caregiver Assessment Take Place?

What Should a Family Caregiver Assessment Include?

While the assessment approach needs to be tailored to your service setting and program, any caregiver assessment should:

- ◆ Identify the primary caregiver and other family and friends who are involved in arranging, coordinating or providing care.
- ◆ Approach issues from the caregiver’s perspective.
- ◆ Improve caregivers’ understanding of their role and what they need to know to carry out tasks.
- ◆ Give practitioners information to develop a care plan with measurable outcomes for caregivers.
- ◆ Address services available for the caregiver and provide appropriate and timely referral for services.
- ◆ Be no longer than necessary.

Experts in serving caregivers and researchers who focus on assessment point to seven categories of information (i.e. the domains or content area) to include in a caregiver assessment:

1. Background on the caregiver and the caregiving situation
2. Caregiver’s perception of health and functional status of the care recipient
3. Caregiver’s values and preferences with respect to everyday living and care provision
4. Health and well-being of the caregiver
5. Consequences of caregiving on the caregiver
6. Care-provision requirements (skills, abilities, knowledge)
7. Resources to support the caregiver.

These categories of information are applicable across settings (e.g., home, hospital, community program) but need not be measured in every assessment. Specific content areas and questions may differ for:

- ◆ Initial assessments compared to reassessments (the latter focus on what has changed over time)
- ◆ New versus continuing care situations
- ◆ An acute episode prompting a change in caregiving versus an ongoing need
- ◆ Type of setting and the focus of services.

The seven recommended categories of information, areas to assess, and possible questions for each area are shown in the following table:

Caregiver Assessment: Information Categories, Areas to Assess and Possible Questions

Information Category	Areas to Assess	Possible Questions
Context	<ul style="list-style-type: none"> ◆ Caregiver relationship to care recipient ◆ Physical environment (home, facility) ◆ Household status (number in home, etc.) ◆ Financial status ◆ Quality of family relationships ◆ Duration of caregiving ◆ Employment status (work/home/ volunteer) 	<ul style="list-style-type: none"> ◆ What is the caregiver's relationship to the care recipient? ◆ How long has he/she been in the caregiving role? ◆ Does the care recipient live in the same household with the caregiver? ◆ Is the caregiver married? Have children? How many people live in the caregiver's household? ◆ Are other family members or friends involved in the care? ◆ Is the caregiver currently employed? Full-time or part-time? ◆ What is the caregiver's household income? ◆ How would the caregiver rate his/her quality of family relationships?

Continued...

Information Category	Areas to Assess	Possible Questions
<p>Caregiver’s Perception of Health and Functional Status of Care Recipient</p>	<ul style="list-style-type: none"> ◆ Activities of daily living (ADLs; bathing, dressing) and need for supervision ◆ Instrumental Activities of Daily Living (IADLs; managing finances, using the telephone) ◆ Psycho-social needs ◆ Cognitive impairment ◆ Behavioral problems ◆ Medical tests and procedures 	<ul style="list-style-type: none"> ◆ Can the care recipient carry out ADLs without assistance (bathing, dressing, etc.)? ◆ Can the care recipient carry out IADLs without assistance (managing finances, shopping)? ◆ Can the care recipient administer his/her medications correctly? ◆ Does the care recipient have any mental health diagnoses or emotional problems? ◆ Does the care recipient have any memory loss or cognitive impairment? ◆ Does the care recipient have any behavioral problems? How frequently do they occur and how much do they bother or upset the caregiver when they happen? ◆ What medical tests and procedures have been done or are needed?
<p>Caregiver Values and Preferences</p>	<ul style="list-style-type: none"> ◆ Caregiver/care recipient willingness to assume/ accept care ◆ Perceived filial obligation to provide care ◆ Culturally based norms ◆ Preferences for scheduling and delivery of care and services 	<ul style="list-style-type: none"> ◆ Is the caregiver willing to assume the caregiver role? Is the care recipient willing to accept care? ◆ Does the caregiver feel he/she is obligated to provide care? ◆ What types of care arrangements are considered culturally acceptable for this family? ◆ What are the caregiver’s (and the care recipient’s) preferences for the scheduling and delivery of care and services?

Continued...

Caregivers Count Too!

Information Category	Areas to Assess	Possible Questions
Well-being of the Caregiver	<ul style="list-style-type: none"> ◆ Self-rated health ◆ Health conditions and symptoms ◆ Depression or other emotional distress (e.g, anxiety) ◆ Life satisfaction/quality of life 	<ul style="list-style-type: none"> ◆ How does the caregiver rate his/her own health? Does the caregiver rate his/her health better, about the same, or worse than it was 6 months ago? ◆ Does the caregiver have any health conditions or symptoms? ◆ How often in the past 6 months has the caregiver had a medical exam or received treatment for physical health problems from a health care practitioner? ◆ Depression Scale (See Selected Measures in Appendix III) ◆ How often does the caregiver feel anxious or angry when he/she is around the care recipient? ◆ How often does the caregiver get a full night's sleep? ◆ How does the caregiver rate his/her life satisfaction and/or quality of life?

Continued...

Information Category	Areas to Assess	Possible Questions
<p>Consequences of Caregiving</p>	<p>◆ Perceived challenges</p> <ul style="list-style-type: none"> • Social isolation • Work strain • Emotional and physical health strain • Financial strain • Family relationship strain • Difficulties with formal providers <p>◆ Perceived benefits</p> <ul style="list-style-type: none"> • Satisfaction of helping family member • Developing new skills and competencies • Improved family relationships 	<p>Perceived challenges</p> <ul style="list-style-type: none"> ◆ Does the caregiver have a social support network or is he/she isolated? ◆ Does the caregiver suffer any work-related difficulties due to the caregiving role? ◆ Does the caregiver suffer from any emotional and/or physical health problems as a result of caregiving? ◆ How much does the caregiver’s health stand in the way of doing things he/she wants to do? ◆ What has been the financial strain, if any, on the caregiver due to his/her caregiving role? ◆ How much disagreement has the caregiver experienced with other family members over particular care issues? <p>Perceived benefits</p> <ul style="list-style-type: none"> ◆ Does the caregiver feel satisfaction in helping a family member? ◆ Does the caregiver feel he/she has developed new skills and knowledge as a result of caregiving? ◆ Has there been an improvement in family relationships (general closeness, communication, similarity of views, degree of getting along) as a result of the caregiving situation?

Continued...

Caregivers Count Too!

Information Category	Areas to Assess	Possible Questions
Caregiver Skills/ Abilities/ Knowledge to Provide Care	<ul style="list-style-type: none"> ◆ Caregiving confidence and competencies ◆ Appropriate knowledge of medical care tasks (wound care, etc.) 	<ul style="list-style-type: none"> ◆ How knowledgeable does the caregiver feel about the care recipient's condition? ◆ What are the skills and abilities needed to provide care for the care recipient? ◆ How would the caregiver rate his/her confidence and competence in these areas? ◆ Does the caregiver have the appropriate knowledge of medical care tasks (wound care, ability to administer medications correctly, etc.) and transfer techniques (moving from bed to chair, etc.)
Caregiver Resources	<ul style="list-style-type: none"> ◆ Helping network and perceived social support ◆ Existing or potential strengths (e.g., what is presently going well) ◆ Coping strategies ◆ Financial resources (health care and service benefits, entitlements such as Veteran's Affairs, Medicare) ◆ Community resources and services (caregiver support programs, religious organizations, volunteer agencies) 	<ul style="list-style-type: none"> ◆ Can the caregiver rely on his/her social support network for help (i.e. respite)? ◆ What are the caregiver's coping strategies? Are these healthy/constructive? ◆ Has the caregiver accessed all financial benefits and entitlements he/she or care recipient is eligible for (e.g., Veteran's Affairs)? ◆ What other community resources/services is the caregiver utilizing or aware of (e.g., caregiver support groups, religious organizations)?

Things to Keep in Mind:

- ◆ Whenever possible, use established measures that are:
 - practical and applicable to family caregivers
 - previously applied, or could be applied, in service settings
 - reliable and valid
 - cited in the literature

(See Selected *Caregiver Assessment Measures: A Resource Inventory for Practitioners* in Appendix II).

- ◆ Be as simple and direct as possible. For example, when adapting a measure developed for research purposes with four response categories (from “strongly agree” to “strongly disagree”), using just two (“agree” and “disagree”) may be sufficient and more practical.
- ◆ Control length by using filter questions and making some sections optional.
- ◆ Know where your caregiver population is coming from and be prepared to meet them. This means being able to communicate in their language and understand their cultural values as these affect caregiving and service use.
- ◆ Administer the assessment questions in a systematic way to all family caregivers.

Who Should Be Assessed?

The Jones Family

Mrs. Jones has been caring for her husband for several months since he had a debilitating stroke, but she is also experiencing bouts of frail health. They've lived in their home together for 35 years. Now Mrs. Jones is finding it increasingly difficult to keep up with household and outdoor chores in addition to managing her husband's care. The Jones' two children help out as much as they can and are active participants in their father's health care. Their oldest son lives nearby and routinely assists with chores and preparing meals. Their other son lives 30 miles away and works the evening shift. He takes Mr. Jones to all of his medical appointments because Mrs. Jones does not feel comfortable driving. A concerned neighbor of the Jones' came across the phone number for the local caregiver support program and called to request assistance for the Jones family.

Should anyone in this situation be assessed? If so, who? Mrs. Jones? Her two sons? The concerned neighbor?

3.10

Keeping in mind that your caregiver assessment approach has to make sense for your program and the resources you have, we offer for your consideration the advice of experts in the field:

- ◆ Anyone who self-identifies as a family caregiver should be offered a caregiver assessment. This inclusive perspective means that a caregiver assessment might be done for any or all of the following:
 - Primary caregiver (spouse, partner, daughter, son)
 - Other family members
 - Friends
 - Neighbors
- ◆ When the assessment involves the primary caregiver and one or more other family members, the assessment may be conducted with everyone together or with the individuals separately. It depends upon what they want and what is feasible logistically.

- ◆ The presence, or absence, of the care recipient during the caregiver assessment also depends upon the situation. Often a caregiver prefers to speak candidly without being heard by the care recipient. But that's not always the case.

Things to Keep in Mind:

- ◆ Not all caregivers identify themselves as such (I'm not a caregiver, I'm his wife—for better or worse...).
- ◆ When multiple family members are involved in caregiving, conflict resolution may be necessary to sort out roles and feelings.

Who Should Conduct a Family Caregiver Assessment?

A range of professionals can conduct a caregiver assessment including:

- ◆ Social Workers
- ◆ Care Managers
- ◆ Nurses
- ◆ Physicians
- ◆ Rehabilitation Professionals
 - i.e., Physical Therapists, Occupational Therapists, Speech Therapists

What Special Training is Needed?

Social service and health care professionals need to know how the assessment process guides and informs their work with the family. Caregiver assessment allows caregivers to “tell their stories” to describe their caregiving situation. However, caregiver assessment is only a tool, not an end in itself. For assessment to matter, the conversation with the caregiver and the information collected must be valued by the practitioner and linked to care planning and what the caregiver wants to happen.

To conduct assessments professionals need to know how to complete forms (increasingly entered online as part of electronic records), and calculate and interpret scores when using standardized measures. They also need to know how to develop a rapport to begin the assessment process, gather information and ask questions, and probe for clarification. When doing caregiver assessments it is also important to recognize and respect diversity and cultural issues, as well as the needs of the caregiver and the care recipient.

Here's what it takes:

Knowledge about...

- Purpose of the assessment
- Self-determination versus safety issues
- Mental health, aging, life-span development issues
- Family systems perspective and conflict resolution
- Resources and brokering, building a community care support network
- Consumer-driven model, the importance of caregiver participation and the strengths-based perspective

Abilities to...

- Buy-in to the purpose of assessment
- Listen
- Deal with emotional content
- Be sensitive to differences in framing questions around culture, religion, age, etc.
- Empathize with the caregiver
- Understand what you know, what you do not and when to hand off
- Have comfort with an educational and self-management approach
- Be aware of personal biases and strong opinions and keep these in check

Skills for...

- Communicating the purpose of assessment to the caregiver
- Interviewing
- Engagement, particularly with people who are not asking for help
- Disseminating information clearly, appropriately and as needed to connect to the care plan

Things to Keep in Mind:

- ◆ Professional differences exist in the approach to assessment. These differences can be strengths that benefit the family.
- ◆ Working as a team and focusing on the “consumer” (i.e. the caregiver) can bridge professional differences. The family comes out ahead!
- ◆ Different techniques, such as direct observation, clinical interview, questionnaires, can be used to obtain information.
- ◆ Consider whether certain parts of the assessment can be self-administered by caregivers.
- ◆ Practitioners who complete assessments should receive adequate training, supervision and feedback on a regular basis about: how to conduct systematic assessments of caregiver needs, how to use specific tools and measures, how to interpret the information collected, and how to work with the family to develop a care plan.

When Should a Family Caregiver Assessment Happen?

As early as possible:

- ◆ Many experts recommend a screening first (see Definitions in Section 1).

Mr. Rodriguez

*Mr. Rodriguez has been caring for his wife Miranda, who has Alzheimer's disease, for more than four years. In addition to managing her finances and preparing all of her meals, he also accompanies her to all of her doctor appointments. At a recent visit to Miranda's primary care physician's office, the receptionist handed him a brief caregiver screening questionnaire. It had five yes or no questions:**

- 1. Do you help someone 60 years of age or older who is not in good health or is not managing as well as he or she used to?*
- 2. Is it ever hard to help this person in any way?*
- 3. Do you ever worry about the health or well-being of this person?*
- 4. Do you ever feel at all stressed when you are helping this person?*
- 5. Would you like more information about services and supports for caregivers?*

Because he responded "yes" to the last question, Mr. Rodriguez was referred to his local Area Agency on Aging. There the caregiver support program specialist asked if he would like to have a complete assessment of his situation. He said yes, so she conducted a full assessment with him. The caregiver specialist was able to respond to Mr. Rodriguez's needs by offering him customized services including a caregiver support group and dementia training.

* Adapted from: The University of Maine (2005). *Maine Primary Partners in Caring Project's Brief Patient Screen*. Available online at: www.umaine.edu/mainecenteronaging/documents/MPPCManFweb.pdf

- ◆ Lots of events can trigger a caregiver assessment. These include:
 - Professional referrals such as those from pharmacists, physicians, clergy, parish nurses, home care workers, Adult Protective Service and the courts
 - Self-referral by the family member
 - Diagnosis of a medical condition
 - Decreased functional status of caregiver or care recipient (e.g., no longer safe to leave care recipient alone)
 - New patient, health plan enrollee or Medicare beneficiary

- Complaint from a care recipient
- Care transitions (e.g., from home to assisted living or to nursing home, or from hospital to home)
- Caregiver workplace issues (e.g., performance or attendance problems)
- Concern from another family member or friend

Assessment should be an ongoing process:

- ◆ Reassessment should occur periodically (e.g., every three to six months). The key question: “Has anything changed?” or “How are things going?”
- ◆ Reassessment may involve a shorter version of the original assessment instrument, reducing the time demands on caregivers and the service agency.
- ◆ Reassessment is needed because:
 - Things change. The care recipient’s or caregiver’s health and functioning may call for a new treatment approach or a shift in the mix of services being offered.
 - We need to know how well the care plan is working. Reassessment is an opportunity to evaluate whether goals have been reached, and if there are any unmet needs.

Things to Keep in Mind:

- ◆ Many family caregivers may be focused on the needs of the care recipient and may not think about their own situation and concerns. Therefore, family caregivers may be more open to a conversation and assessment of their own needs once an immediate crisis has passed or some support has been put into place.

Where Should a Family Caregiver Assessment Take Place?

Mrs. Watkins

Elizabeth Watkins lives in rural West Virginia and is caring for her husband, Roy, who has dementia. She wants to talk about the issues involved in caring for him and seek help, but feels isolated because of her geographic location. Her husband is constantly with her, except for short periods when she goes to the store. She contacted the closest Area Agency on Aging (45 minutes away) to get more information on caregiving and dementia. She was offered an in-person assessment but Elizabeth felt that the agency was too far away to travel to and she was uneasy leaving her husband alone. Where should Elizabeth's assessment take place?

The simple answer is: in a private setting that is convenient to the caregiver. In the case of Elizabeth, the social worker suggested conducting the assessment over the phone right away and scheduling a visit to their home in three weeks, at a time when Roy usually is napping. Experts generally agree that having a home visit be part of the assessment process is a good idea, in order for the person conducting the assessment to understand the home environment. But sometimes that is not practical.

3.17

Be Flexible & Creative! Offer Assessments:

- At home
- In a coffee shop or local restaurant
- At a community agency
- At the caregiver's workplace or after work hours
- On the weekends
- Together with or separately from the care recipient.

Things to Keep in Mind:

- ◆ When caregivers would like to have the assessment conducted separately from the care recipient, it may be a good idea to offer respite for caregivers who cannot leave their loved one unattended.

Fundamental Principles for Caregiver Assessment³

The National Consensus Development Conference *for* Caregiver Assessment produced seven fundamental principles to guide caregiver assessment policy and practices:

1. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess and address their needs.
2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.
3. Caregiver assessment should result in a care plan (developed collaboratively with the caregiver), that indicates the provision of services and intended measurable outcomes.
4. Caregiver assessment should be multidimensional in approach and periodically updated.
5. Caregiver assessment should reflect culturally competent practice.
6. Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners and service providers' education and training should equip them with an understanding of the caregiving process and its impacts, as well as the benefits and elements of an effective caregiver assessment.
7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.

³ Source: Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change*. Report from a National Consensus Development Conference (Vol. I) San Francisco: Author.

Caregivers Count Too!

A Toolkit to Help Practitioners Assess
the Needs of Family Caregivers

Section 4 Wrapping Up

Next Steps

Appendix I:
Examples of Caregiver Assessment Tools

Appendix II:
FCA Resources on Caregiver Assessment

Appendix III:
Selected Annotated Bibliography for Caregiver Assessment



Section 4

Wrapping Up

Next Steps

Now it's up to you to take action. We hope that we've convinced you about the central importance of incorporating family caregivers, and an assessment of their own needs, into your everyday practice. We also hope that we've given you the basic tools and strategies to create and implement a caregiver assessment approach that works in your practice setting.

We know that policymakers and program administrators have many other concerns that we have not been able to address in this toolkit. Among them are three important ones: obtaining funding and reimbursement for caregiver assessment; using computer applications, such as a uniform tracking system, to streamline or ease the assessment process; and finding appropriate ways to connect the assessments of the care recipient and caregiver to eliminate duplication yet protect privacy and autonomy.

We encourage you to draw upon Volumes I & II of the National Consensus Development Conference for Caregiver Assessment reports (see Appendix II for citation). Many of these policy and administrative issues are addressed there.

We hope that you, the practitioner, will join us in embracing a family-centered care perspective and become an advocate for the changes needed in the current health and long-term care systems.

Appendix I: Examples of Caregiver Assessment Tools

California

California uses a distinct assessment tool within a state-funded caregiver support program (the statewide system of 11 California Resource Centers) to examine the needs/situations of family caregivers to aid in care planning and service development.

Massachusetts

Massachusetts is examining a uniform assessment process for Medicaid Home and Community-Based Services (HCBS) by testing the use of a new caregiver assessment component. This component identifies the primary family caregiver as a distinct consumer in the HCBS system, integrating family caregiver support into a broader systems framework. The full assessment may also be downloaded from: www.adrc-tae.org/documents/MA%20Real%20Choice%20Functional%20Assessment%20Tool%20-%20FOR%20REVIEW%20ONLY.doc?PHPSESSID=38454d09080453df80acca64dc770ce.

Minnesota

Minnesota includes a caregiver assessment as part of the state's uniform assessment process to access publicly funded long-term care services. The full assessment may also be downloaded from: <http://edocs.dhs.state.mn.us/lfserver/Legacy/DHS-3428-ENG>

Pennsylvania

Pennsylvania uses a uniform assessment process with a caregiver component for all publicly funded programs for older people and their families. The full assessment may also be downloaded from: www.aging.state.pa.us/longtermcare/lib/longtermcare/Downloadables/COAF.pdf

Washington

Washington includes a caregiver component as part of the state's uniform assessment tool for all HCBS programs for older people and adults with disabilities. Currently state officials are working toward developing a comprehensive caregiver assessment.

Other – American Medical Association (AMA)

The AMA has developed and tested an 18-item Caregiver Self-Assessment Questionnaire to encourage physicians and health practitioners to recognize and support family caregivers. The full assessment may also be downloaded from: www.ama-assn.org/ama/upload/mm/36/caregivertooleng.pdf

CRC Site Code ___ / Client Code _____

- F. Think of the help you get from all your family and friends in looking after [CR]. Please identify the one response that most closely identifies your help situation: *(Circle only one.)*
- 1. I receive no help
 - 2. I receive far less help than I need
 - 3. I receive somewhat less help than I need
 - 4. I receive about what I need in terms of help
 - 5. I don't need any help

IV. FUNCTIONAL LEVEL OF THE CARE RECEIVER: *Ask regardless of placement status.*

Does [CR] currently have problems with the following activities?	NO	YES	DON'T KNOW N/A	COMMENTS
A. Eating	0	1	9	
B. Bathing/showering	0	1	9	
C. Dressing (choosing/putting on appropriate clothing)	0	1	9	
D. Grooming (brushing hair, teeth)	0	1	9	
E. Using the toilet	0	1	9	
F. Incontinence	0	1	9	
G. Transferring from bed/chair/car	0	1	9	
H. Preparing meals	0	1	9	
I. Staying alone, must be supervised	0	1	9	
J. Taking medications	0	1	9	
K. Managing money or finances	0	1	9	
L. Performing household chores	0	1	9	
M. Using the telephone	0	1	9	
N. Mobility	0	1	9	
O. Wandering, or the potential to wander	0	1	9	

4.5

- P. Which functional problems cause you the most concern in caring for [CR]?

- Q. Does [CR] still drive? No Yes
- a. If YES, do you have concerns? What are they? _____
 - b. If YES, do you know the Department of Motor Vehicles (DMV) and medical reporting guidelines? No Yes

V. MEMORY AND BEHAVIORAL PROBLEMS

Family Consultant: Please hand the Revised Memory and Behavior Problems Checklist to the caregiver for him/her to complete (located on pages 9-11). If the caregiver is unable to complete unassisted, please read the checklist and responses to the caregiver and record his/her responses. After the caregiver has completed the RMBPC, review the form and select the problems that cause the caregiver the most upset to discuss in the following question.

- A. You have indicated that _____ cause(s) you concern.
Please tell me more about [CR's] difficulties and your individual concerns.

VI. HEALTH

- A. Does [CR] have health insurance? 0. No 1. Yes If yes, what type? _____
- B. Does [CR] have prescription drug coverage? 0. No 1. Yes
- C. What is the annual out-of-pocket expense for prescription drugs for [CR]? \$ _____
- D. Does [CR] have California Advance Health Care Directive? 0. No 1. Yes
- E. Do you have health insurance? 0. No 1. Yes If yes, what type? _____
- F. Do you have prescription drug coverage? 0. No 1. Yes
- G. What is the annual out-of-pocket expense for prescription drugs for you? \$ _____
- H. Do you have California Advance Health Care Directive? 0. No 1. Yes
- I. How would you rate your overall health at this time?
1. Excellent 2. Good 3. Fair 4. Poor
- J. Is your health now better, about the same, or worse than it was 6 months ago?
1. Better 2. About the same 3. Worse
- K. How often in the past 6 months have you had a medical examination or received treatment for physical health problems from a health care practitioner? _____ times
- L. Please indicate which of the following health problems you have experienced in the past 12 months. (Circle all that apply.)
- | | | | |
|-----------------------|------------------------|--------------------------|--|
| 1) Allergies | 7) High cholesterol | 12) Blood pressure level | 17) Broken bone/osteoporosis |
| 2) Arthritis | 8) Dental | 13) Respiratory/asthma | 18) Cardiovascular disease/
heart trouble |
| 3) Back/neck | 9) Diabetes | 14) Stomach | 19) Gynecological/menopausal |
| 4) Blood/liver/kidney | 10) Eyes/ears/nose | 15) Sleep disturbance | 20) Thyroid/endocrinology |
| 5) Bowel | 11) Infectious disease | 16) Weight | 21) Headaches/migraines |
| 6) Cancer | 22) Other _____ | 23) None | |



CRC Site Code ___ / Client Code _____

M. Have you experienced anxiety or depression in the past 12 months? 0.No 1.Yes

a. If YES, please describe your experience. _____

b. If YES, have you received help? What type? Was the intervention helpful?

c. If YES, do you currently have thoughts about suicide? If YES, do you have a plan?

If YES, then follow the Suicide Protocol contained in the Operations Manual.

N. How much does your health stand in the way of your doing the things you want to do?

0. Not at all 1. A little 2. Moderately 3. Very much

O. When under stress, caregivers sometimes find that their drinking and/or drug use increases. Is that a concern for you? Has someone you know expressed that concern for you?

P. If you are currently taking prescription medication, are you experiencing difficulties managing your medications (overuse, under-use, adverse effects, etc.)?

Q. In addition to caregiving, have you recently had a major stress in your life such as a death, job loss, or divorce?

VII. ADAPTED ZARIT INTERVIEW (*Bédard et al. 2001*)

Family Consultant: Please read the Adapted Zarit Interview exactly as it is written in order to maintain the validity of the scale. Do not hand the paper to the caregiver to complete. See the Instruction Manual for further directions.

DO YOU FEEL...	NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS
A. ...that because of the time you spend with [CR] that you don't have enough time for yourself?	0	1	2	3	4
B. ...stressed between caring for [CR] and trying to meet other responsibilities (work/family)?	0	1	2	3	4
C. ...angry when you are around the care receiver?	0	1	2	3	4
D. ...that [CR] currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
E. ...strained when you are around [CR]?	0	1	2	3	4
F. ...that your health has suffered because of your involvement with [CR]?	0	1	2	3	4
G. ...that you don't have as much privacy as you would like because of [CR]?	0	1	2	3	4
H. ...that your social life has suffered because you are caring for [CR]?	0	1	2	3	4
I. ...that you have lost control of your life since [CR]'s illness?	0	1	2	3	4
J. ...uncertain about what to do about [CR]?	0	1	2	3	4
K. ...you should be doing more for [CR]?	0	1	2	3	4
L. ...you could do a better job in caring for [CR]?	0	1	2	3	4

_____/

VIII. OTHER CAREGIVING ISSUES AND PLACEMENT

A. (*Optional*) Sometimes a person who is caregiving experiences changes in his/her personal or intimate relationships, as a result of caregiving. Are there relationship issues you would like to discuss?

B. Would you consider moving [CR] to a facility? What issues might cause you to seriously consider placement? (*e.g. incontinence, aggression, wandering, falls, your physical health or exhaustion, financial or emotional strain*)



IX. CAREGIVER AND CARE RECEIVER DEMOGRAPHICS

- A. In what year did you begin caregiving? _____
- B. Are you currently employed?
- | | | |
|--|---------------------|------------|
| 1. Full-time (35 hours/week or more) | 3. Leave of absence | 5. Retired |
| 2. Part-time (less than 35 hours/week) | 4. Not Employed | |
- C. Has your employment status changed because of caregiving duties? (Circle all that apply.)
- | | | |
|-------------------------|---------------------|--------------|
| 1. No change | 5. Increased hours | 9. Quit job |
| 2. Changed jobs | 6. Decreased hours | 10. Laid off |
| 3. Family/medical leave | 7. Early retirement | 11. Other |
| 4. Leave of absence | 8. Began working | |
- D. What is your highest level of education?
- | | | |
|--------------------------|----------------------------|----------------------|
| 1. Less than high school | 4. Some college coursework | 7. Declined to state |
| 2. Some high school | 5. College graduate | |
| 3. High school graduate | 6. Post-graduate degree | |
- E. What is your current marital status?
- | | |
|--------------|--------------------------------------|
| 1. Married | 4. Widowed |
| 2. Separated | 5. Living together/domestic partners |
| 3. Divorced | 6. Single |
- F. What is your annual household income level? (Include income of all persons in the household who share expenses.)
- | | | |
|------------------------|------------------------|--------------------------------|
| 1. Under \$9,000 | 4. \$20,000 – \$39,999 | 7. \$80,000 – \$99,999 |
| 2. \$9,000 – \$11,999 | 5. \$40,000 – \$59,999 | 8. \$100,000 or above |
| 3. \$12,000 – \$19,999 | 6. \$60,000 – \$79,999 | 9. Caregiver declined to state |
- G. What is [CR's] and spouse's (when applicable) annual income level? (Not household income: exclude the income of other individuals even if they live in the same household. DO NOT LEAVE BLANK: if the same as the previous question, please circle again.)
- | | | |
|------------------------|------------------------|--------------------------------|
| 1. Under \$9,000 | 4. \$20,000 – \$39,999 | 7. \$80,000 – \$99,999 |
| 2. \$9,000 – \$11,999 | 5. \$40,000 – \$59,999 | 8. \$100,000 or above |
| 3. \$12,000 – \$19,999 | 6. \$60,000 – \$79,999 | 9. Caregiver declined to state |
- H. Does someone hold durable power of attorney for finances for [CR]? 0.No 1.Yes
If YES, what is his/her relationship with [CR]? _____
- I. Please identify any additional caregiving responsibilities for other people that may apply.
- | | |
|--|---|
| 1. Dependent minor(s) without disability | 3. Adult(s) without disability (e.g. frail elder) |
| 2. Dependent minor(s) with disability | 4. Adult(s) with disability |

X. INFORMATION NEEDS

- A. How knowledgeable do you feel about [CR’s] disease/disorder?
 0. Not at all 1. A little 2. Moderately 3. Very
- B. How familiar are you with programs/resources available to help you?
 0. Not at all 1. A little 2. Moderately 3. Very

Do you need information about:

NO	YES
----	-----

- | | | |
|---|---|---|
| C. ...education or training classes on how to care for yourself as a caregiver? | 0 | 1 |
| D. ...education or training classes on how to care for [CR]? | 0 | 1 |
| E. ...community resources, such as a meal-delivery service or a transportation service? | 0 | 1 |
| F. ...finding someone to help to take care of [CR] during the day in his/her home or about short-term respite in a facility? | 0 | 1 |
| G. ...about a camp for [CR] or a retreat for you? | 0 | 1 |
| H. ...adult day programs that [CR] could attend? | 0 | 1 |
| I. ...legal and financial issues related to caregiving (e.g. durable power of attorney, living will, trusts, legal guardian/conservator, etc.)? | 0 | 1 |
| J. ...helping you plan for the care of [CR], such as financial benefits and long term care planning (e.g. Medi-Cal, Social Security, IHSS, etc.)? | 0 | 1 |
| K. ...placing [CR] in an assisted living or skilled nursing facility? | 0 | 1 |
| L. ...the opportunity to talk with a group of people who are in a similar situation, such as a support group? | 0 | 1 |
| M. ...professional counseling options? | 0 | 1 |
| N. ...online caregiving information sites and support groups? | 0 | 1 |

4.10

CRC Site Code ___ / Client Code _____

XI. CARE PLAN: PLAN OF ACTION BY CRC STAFF

For each type of service, write the number of the service code or codes that apply to the caregiver's plan of action. More than one service code may apply for a type of service. If the type of service is not listed, use rows 22-24 and write the type of service in the Comments column.

SERVICE CODES	
1.	CRC provided service (1658 funds)
2.	CRC provided service (non-1658 funds)
3.	Waitlist
4.	External referral
5.	Referral refused
6.	Service needed but not available
7.	Already receiving service

TYPE OF SERVICE	SERVICE CODE(S)	COMMENTS
1. Follow-Up Info & Referral		
2. Family Consultation		
3. Counseling: Individual		
4. Support Group		
5. Psychoeducational Group		
6. Education/Training		
7. Geriatric/Medical Evaluation		
8. Neuropsychological Consultation		
9. Legal/Financial Consultation		
10. Respite: Adult Day Care		
11. Respite: In-home		
12. Respite: Out-of-home		
13. Caregiver Retreat		
14. Respite: Camp for care receiver		
15. Transportation		
16. Link2Care		
17. Case Management		
18. Home Health Services		
19. Hospice		
20. Home Maker/Chore Worker		
21. Help with Placement		
22. Other (Specify under Comments)		
23. Other (Specify under Comments)		
24. Other (Specify under Comments)		

V. MEMORY AND BEHAVIORAL PROBLEMS (Teri et al. 1992)

The following is a list of problems care receivers sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY

Indicate if any of these problems occurred during the past week.

REACTION

If the problem has occurred in the past week, how much has this bothered or upset you when it happened?

If your response is one of the three shaded responses below, please report your reaction.

	Don't Know N/A	Never occurred	Not in the past week	1 to 2 times	3 to 6 times	Daily or more often	Don't Know N/A	Not at all	A little	Moderately	Very Much	Extremely
1. Asking the same question over and over.												
2. Trouble remembering recent events (e.g., items in the newspaper or on TV).												
3. Trouble remembering significant past events.												
4. Losing or misplacing things.												
5. Forgetting what day it is.												
6. Starting but not finishing things.												
7. Difficulty concentrating on a task.												
8. Destroying property.												

CRC Site Code ____ / Client Code ____

FREQUENCY

Indicate if any of these problems occurred during the past week.

REACTION

If the problem has occurred in the past week, how much has this bothered or upset you when it happened?

If your response is one of the three shaded responses below, please report your reaction.

	Don't Know N/A	Never occurred	Not in the past week	1 to 2 times	3 to 6 times	Daily or more often	Don't Know N/A	Not at all	A little	Moderately	Very Much	Extremely
9. Doing things that embarrass you.												
10. Waking you or other family members up at night.												
11. Talking loudly and rapidly.												
12. Appears anxious or worried.												
13. Engaging in behavior that is potentially dangerous to self or others.												
14. Threats to hurt oneself.												
15. Threats to hurt others.												
16. Aggressive to others verbally.												
17. Appears sad or depressed.												

CRC Site Code ____ / Client Code ____

FREQUENCY

Indicate if any of these problems occurred during the past week.

If your response is one of the three shaded responses below, please report your reaction.

REACTION

If the problem has occurred in the past week, how much has this bothered or upset you when it happened?

	Don't Know N/A	Never occurred	Not in the past week	1 to 2 times	3 to 6 times	Daily or more often	Don't Know N/A	Not at all	A little	Moderately	Very Much	Extremely
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens," "I never do anything right").												
19. Crying and tearfulness.												
20. Commenting about death of self or others (e.g., "Life isn't worth living," "I'd be better off dead").												
21. Talking about feeling lonely.												
22. Comments about feeling worthless or being a burden to others.												
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.												
24. Arguing, irritability, and/or complaining.												

4.14

XII. CAREGIVER QUESTIONNAIRE (Radloff 1977)

Below is a list of the ways you (the caregiver) may have felt or behaved recently. For each statement, check the box that best describes how often you have felt this way during the past week.

DURING THE PAST WEEK:		Rarely or None of the Time (Less than 1 day)	Some of the Time (1-2 days)	Occasionally (3-4 days)	Most of the Time (5-7 days)
A.	I was bothered by things that don't usually bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B.	I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.	I felt that I could not shake the blues even with help from my family and friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D.	I felt that I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E.	I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F.	I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G.	I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H.	I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I.	I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J.	I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K.	My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L.	I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M.	I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
N.	I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O.	People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
P.	I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q.	I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
R.	I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S.	I felt that people disliked me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T.	I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.15

Massachusetts

UMASS Center for Health Policy and Research

Real Choice Pilot Project Program

FOR REVIEW PURPOSES ONLY

15. **How many meals do you typically eat each day?**
 0-1 meals (if "Yes", please complete Level 3, Nutritional Risk Screen Module on page 41)
 2 meals (if "Yes", please complete Level 3, Nutritional Risk Screen Module on page 41)
 3 meals
 More than 3 meals

16. **What is your current weight?** _____

17. **If you do not know your current weight, have you been weighed at your doctor's office in the past year?**
 Yes No If no, why not? _____

Comments:

SECTION H: UNPAID SUPPORTS/CAREGIVER STATUS

<p>1. Do you have someone who helps you on a regular basis? <input type="checkbox"/> No <input type="checkbox"/> Yes (if "Yes" is checked, please complete Level 3, Informal Support Module on page 37)</p> <p>2. What is this person's relationship to you? <input type="checkbox"/> Child or child-in-law <input type="checkbox"/> Spouse <input type="checkbox"/> Parent <input type="checkbox"/> Other Relative <input type="checkbox"/> Friend/neighbor <input type="checkbox"/> Other _____</p> <p>3. Does this person live with you? <input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Contact Information: Name: _____ Address: _____ Town: _____ State: _____ Zip Code: _____ Phone: _____</p>
<p>4. Do you have a backup or second person to help you? <input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p>5. What is this person's relationship to you? <input type="checkbox"/> Child or child-in-law <input type="checkbox"/> Spouse <input type="checkbox"/> Parent <input type="checkbox"/> Other Relative <input type="checkbox"/> Friend/neighbor <input type="checkbox"/> Other _____</p> <p>6. Does this person live with you? <input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Contact Information: Name: _____ Address: _____ Town: _____ State: _____ Zip Code: _____ Phone: _____</p>
<p>7. Do you feel safe with the people who enter your home? <input type="checkbox"/> Yes <input type="checkbox"/> No (If "No" is checked, please answer Level 3, Abuse and Neglect Module on page 29)</p> <p>8. Is there anyone who comes to your home that makes you feel uneasy? <input type="checkbox"/> Yes <input type="checkbox"/> No (If "No" is checked, please answer Level 3, Abuse and Neglect Module on page 29)</p>	

FOR REVIEW PURPOSES ONLY

MODULE B: CAREGIVER/SUPPORT PERSON STRESS

This module is to be completed by a caregiver or support person only based upon specific request. This module measures an individual's risk of caregiver stress, and provides a score indicating the level of risk.

1. How would you describe your caregiver status?

- I'm unable to continue in caring activities—e.g. decline in my health makes it difficult to continue
- I'm not satisfied with the support received from family and friends (e.g. other children of client)
- I feel distressed, angry or depressed
- None of above

2. How would you rate your health?

- Excellent
- Very good
- Good
- Fair
- Poor

- | | | |
|------------------------------|-----------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 3. Is your sleep disturbed? (e.g. because your loved one is in and out of bed or wanders around at night) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 4. Do you find your care giving role inconvenient? (e.g. because helping takes so much time or it's a long drive over to help) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 5. Do you find your caregiver role a physical strain? (e.g. because of lifting in and out of a chair; effort or concentration is required) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 6. Do you find your caregiver role confining? (e.g. helping restricts free time or cannot go visiting) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 7. Have you found you've had to make family adjustments due to your care giving role?? (e.g. because helping has disrupted routine; there has been no privacy) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 8. Have you had to make changes in personal plans due to your care giving role? (e.g. had to turn down a job; could not go on vacation) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 9. Have you found there have been other demands on your time? (e.g. from other family members) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 10. Have you had to make emotional adjustments due to your care giving role? (e.g. because of severe arguments) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 11. Have you found some behavior upsetting? (e.g. because of incontinence; your loved one has trouble remembering things or he or she accuses people of taking things) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 12. Is it upsetting to find that your loved one has changed so much from his/her former self? (e.g. he/she is a different person than he/she used to be) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 13. Have you had to make work adjustments due to your care giving role? (e.g. because of having to take time off) |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 14. Have you found your role as a caregiver a financial strain? |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | 15. Are you feeling completely overwhelmed? (e.g. because of worry about my loved one; concerns about how you will manage) |

Total Score: Count "Yes" responses. Any positive answer may indicate a need for intervention in that area. A score of "7" or higher indicates a high level of stress.

Comments:

4.17

FOR REVIEW PURPOSES ONLY

MODULE G: INFORMAL SUPPORT

This module assesses a person's level and type of informal support received and from whom. It also assesses a person's preference for paid versus unpaid support.

1. What kind of help does your caregiver/support person provide?

- Advice or emotional support
- Help with instrumental activities of daily living (IADL support such as preparing meals, answering telephone, shopping)
- Help with activities of daily living (ADL support such as bathing, dressing, going to the bathroom)
- Environmental support (housing, home maintenance)
- Psychosocial support (socialization, companionship, recreation)
- Advocates or facilitates participation in health care
- Financial agent, conservator, or power of attorney

2. If needed, is your support person or caregiver willing (and able) to increase help in the following areas?

Advice or emotional support

- more than 2 hours
- 1-2 hours per day
- no

IADL care

- more than 2 hours
- 1-2 hours per day
- no

ADL care

- more than 2 hours
- 1-2 hours per day
- no

3. Do you prefer to have a paid employee provide assistance with your daily activities, or do you prefer to have your support person/caregiver provide assistance?

- I would like to have a paid employee instead of my informal support person/caregiver
- I would like to have my informal support person/caregiver provide assistance

4. Does your support person/caregiver have other responsibilities (such as work or other family obligations), physical conditions or health problems that would make it difficult for him or her to help you?

- No
- Yes If yes, please explain: _____

5. Has your support person/caregiver expressed the need for relief?

- Yes If yes, please explain: _____

Comments:

4.18

Minnesota

P. Caregiver Assessment

RI

R2

(Introduce yourself to caregiver.) (NAME OF REFERRAL OR PERSON) told us you were the person most involved in helping with (NAME OF PERSON's) care, so we have a few questions for you.

Relationship to care receiver: _____

P.1 First, how often do you give care to (NAME OF PERSON)? Would you say you give care:

- Every day Less than once a week At least once a week
 Several times a week Don't know

P.2 What kind of help do you give (NAME OF PERSON)? *(ASK:)* Do you give.

	Yes	Comments
Personal care (such as help with bathing, dressing, using the toilet, getting in and out of the bath, and feeding)	<input type="checkbox"/>	_____
Housekeeping (such as help with meal preparation, cleaning and laundry)	<input type="checkbox"/>	_____
Transportation	<input type="checkbox"/>	_____
Shopping and errands	<input type="checkbox"/>	_____
Supervision for safety	<input type="checkbox"/>	_____
Money management	<input type="checkbox"/>	_____
Other	<input type="checkbox"/>	_____
(SPECIFY) _____		

P.2a How long have you been helping (NAME OF PERSON) with this care? _____

P.3 In the last two weeks, how many hours did you spend giving care to (NAME OF PERSON)? _____ hours in last two weeks

P.4 Are you employed full-time, part-time, or are you not employed?

- Full-time Part-time Not working

P.5 If you were unable to continue with care, who would take your place?

- Nobody Other (SPECIFY) _____

P.6 How is your own health? Would you say it is excellent, good, fair or poor?

- Excellent Good Fair Poor No response

P.7 Considering the care you provide for (NAME OF PERSON), I would like to ask you if various aspects of your life have become worse, the same, or better. Let's start with...

	Worse	Same	Better	Don't Know	Comments/ Plan Implications
a. Relationship with (PERSON)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
b. Relationships with other family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
c. Relationships with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
d. Your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
e. (IF APPLICABLE:) Your work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
f. Your emotional well-being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

4.19

P.8 Is there anything that makes it difficult for you to provide care to (person's name)?
 Yes (DESCRIBE) _____

 _____ No
 Do you have any concerns about caring for (person), either about yourself, other family members or (person name) _____

RI

R2

Assessor: P.9 List any factors that may limit caregiver:		Yes	Yes
Job restricts caregiving	<input type="checkbox"/>	Caregiver has difficulty making appropriate decisions	<input type="checkbox"/>
Family responsibilities restrict caregiving	<input type="checkbox"/>	Caregiver financially dependent upon person	<input type="checkbox"/>
Limited knowledge to manage care	<input type="checkbox"/>	Caregiver may have mental health/substance abuse	<input type="checkbox"/>
Caregiver is physically impaired	<input type="checkbox"/>	Other (SPECIFY) _____	<input type="checkbox"/>
Person's needs are heavy physical burden for caregiver	<input type="checkbox"/>	None	<input type="checkbox"/>
Person's needs are heavy emotional burden for caregiver	<input type="checkbox"/>		
Caregiver's finances limit caregiving potential	<input type="checkbox"/>		

P.10 How would you rate your level of burden in caring for (NAME OF PERSON)?
 None Low Medium High

P.11 What caregiver services are you presently receiving? (e.g. respite, care planning, training, information, care coordination, coaching, etc.)
 None Other _____

P.12 What services or community support would help you, the caregiver, to keep providing care for (NAME OF PERSON) to help keep him/her living in the community?

P.13 Would you like to be contacted by a community organization that can give you more information and assistance with caregiving?
 Yes No

Assessor: If the caregiver is presently receiving supportive services or answered "yes" to P.13, code 27-F in Section K of this form and in Section G on LTC SDoc (Services Plan)

Comments On Caregiver/Community Support Plan Implications:

4.20

Pennsylvania

SECTION 9: INFORMAL SUPPORTS

1. Does consumer have any informal supports?
 No, Skip to page 17, Section 10, Question 1. Yes, continue . . .

2. List Informal Supports Name/Location/Phone	Relationship P = Primary caregiver	Age	NARRATIVE: Help Provided

3. If the people who help you are not available, are there other persons who will assist you if asked? Yes No
 Who are they? _____

4. Check limitations or constraints on primary caregiver.

- | | |
|--|---|
| <input type="checkbox"/> No particular constraints
<input type="checkbox"/> Poor health, disabled, frail
<input type="checkbox"/> Employed
<input type="checkbox"/> Lacks knowledge, skills
<input type="checkbox"/> Providing care to others
<input type="checkbox"/> Not reliable | <input type="checkbox"/> Poor relationship with consumer
<input type="checkbox"/> Lives at a distance
<input type="checkbox"/> Alcohol, drug abuse
<input type="checkbox"/> Financial strain
<input type="checkbox"/> Dependent on consumer for housing, money or other |
|--|---|

4.21

PRIMARY CAREGIVER INFORMATION (important when considering FCSP)

5. Current employment status? (full/part time) _____
6. Have your caregiving and social life and/or employment affected each other? How? _____

7. Do you have any other caregiving responsibilities? (children, other adults, etc.) _____
8. How many hours a day do you have available to provide care to this consumer? _____
9. How many hours a day do you usually spend providing care to this consumer? _____
10. Describe problems with continued caregiving (if any). _____

11. Overall, how stressed do you feel in caring for the consumer? (Optional caregiver stress interview may be completed at this point in the assessment - see pg. 25)
 Not stressed Somewhat stressed Very stressed
12. Do you desire service or support?
 No Yes, Describe needs _____

PRIMARY CAREGIVER INFORMATION (Continued)

13. Is anyone available to provide respite (relief) when you are unable to provide care? Yes No If yes, is such assistance available on short notice? Yes No

14. In the past six months, have there been any significant changes or events in your life? Yes No Explain:

15. Are you currently experiencing any emotional concerns or difficulties? Yes No Explain:

16. Are you currently receiving any assistance to deal with your emotional concerns or difficulties? Yes No Explain:

17. Do you participate in a support or discussion group where you can discuss your feelings? Yes No What type of support group/frequency of attendance?

18. Have you ever been so upset that you did something to your relative (consumer) that you now regret? Yes No Explain:

19. Has your relative (consumer) ever done these kinds of things to you? Yes No Explain:

20. Consumable Caregiving Supplies

Item Description	Total Average Monthly Costs	Who Pays

21. What is the average monthly cost TO THE FAMILY OR CONSUMER for consumable supplies?

22. Comments

FORMAL SERVICES

What services are you currently receiving from an agency or organization?

Have you received any **other** services in the past 6 months? What were they?

Are there any services that are scheduled to begin sometime soon? What are they?

(If in the hospital or nursing facility)

Are you receiving physical therapy . . . occupational therapy . . . speech therapy?

Are there any services that are scheduled to begin when you go home . . . (or when you get to the nursing facility?)

SECTION 13: PREFERENCES

1. What are the consumer's preferences for receiving needed care?

2. What are the family's preferences for the consumer's care?

3. Comments.

4. Is referral to PS indicated? No Yes, complete REPORT OF NEED

Note: If DC/PCH is being considered, complete the Placement Options Information Section on page 24.

4.24


Caregiver Stress Interview (Steven H. Zarit, Ph.D. - modified version)

Read to Caregiver: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

QUESTION	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?					
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed over your relative's behavior?					
5. Do you feel angry when you are around your relative?					
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?					
7. Are you afraid of what the future holds for your relative?					
8. Do you feel your relative is dependent upon you?					
9. Do you feel strained when you are around your relative?					
10. Do you feel your health has suffered because of your involvement with your relative?					
11. Do you feel that you don't have as much privacy as you would like because of your relative?					
12. Do you feel that your social life has suffered because you are caring for your relative?					
13. Do you feel uncomfortable about having friends over because you are caring for your relative?					
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15. Do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of your relative much longer?					
17. Do you feel you have lost control of your life since your relative's illness?					
18. Do you wish you could just leave the care of your relative to someone else?					
19. Do you feel uncertain about what to do about your relative?					
20. Do you feel you should be doing more for your relative?					
21. Do you feel you could do a better job in caring for your relative?					
22. Overall, do you feel burdened caring for your relative?					

4.25

To be completed by Case Manager:

TOTAL ZARIT SCORE

Washington

CAREGIVER STATUS						
CAREGIVER LIST						
LAST NAME			FIRST NAME			
CAREGIVER DETAIL						
DO YOU LIVE WITH THE CLIENT?		IF NO, WHAT IS THE DISTANCE YOU LIVE FROM THE CLIENT?		HOW LONG HAVE YOU BEEN PROVIDING CARE?		
<input type="checkbox"/> Yes <input type="checkbox"/> No		_____ Miles		_____ Months _____ Years		
SUPPORT SERVICES						
ARE YOU CURRENTLY USING ANY CAREGIVER SUPPORT SERVICE(S)?			IF YES, WHAT AND HOW OFTEN			
<input type="checkbox"/> Yes <input type="checkbox"/> No			<input type="checkbox"/> Caregiver Education/Conferences <input type="checkbox"/> One-on-one Training <input type="checkbox"/> Support Group <input type="checkbox"/> Counseling <input type="checkbox"/> Respite care services			
STRESS BARRIERS						
OVERALL HOW STRESSED DO YOU FEEL IN CARING FOR THE CLIENT?			ARE THERE ISSUES/ OBSTACLES THAT MAKE YOU AT RISK OF NOT BEING ABLE TO CONTINUE CAREGIVING?			
<input type="checkbox"/> Not Stressed <input type="checkbox"/> Somewhat Stressed <input type="checkbox"/> Very Stressed			<input type="checkbox"/> Yes <input type="checkbox"/> No			
BARRIERS TO CONTINUED CAREGIVING						
<input type="checkbox"/> Decline in own emotional health <input type="checkbox"/> Employment is negatively impacted <input type="checkbox"/> Need (more) breaks from caregiving <input type="checkbox"/> Decline in own physical health <input type="checkbox"/> Has other caregiving responsibility <input type="checkbox"/> Relationship issues with client/family <input type="checkbox"/> Does not have necessary training/skills <input type="checkbox"/> Level of caregiving is too difficult						
Do you feel . . .		Never	Rarely	Sometimes	Quite Frequently	Nearly Always
that because of the time you spend with the client that you don't have enough time for yourself?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
stressed between caring for the client and trying to meet other responsibilities (work/family)?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
angry when you are around the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that the client currently reflects your relationship with family members or friends in a negative way?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
strained when you are around the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that your health has suffered because of your involvement with the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that you don't have as much privacy as you would like because of the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that your social life has suffered?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that you lost control of your life since the client's illness?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
uncertain about what to do about the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
you should be doing more for the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
you could do a better job in caring for the client?		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

American Medical Association

*Caregiver Self-Assessment
Questionnaire*

How are you?

American Medical Association
Physicians dedicated to the health of America



Caregivers are often so concerned with caring for their relative’s needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

- | | |
|--|---|
| <p>1. Had trouble keeping my mind on what I was doing<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>2. Felt that I couldn’t leave my relative alone.....<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>3. Had difficulty making decisions<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>4. Felt completely overwhelmed.....<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>5. Felt useful and needed<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>6. Felt lonely<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>7. Been upset that my relative has changed so much from his/her former self.....<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>8. Felt a loss of privacy and/or personal time<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>9. Been edgy or irritable<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>10. Had sleep disturbed because of caring for my relative<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>11. Had a crying spell(s)<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>12. Felt strained between work and family responsibilities.....<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>13. Had back pain<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>14. Felt ill (<i>headaches, stomach problems or common cold</i>)<input type="checkbox"/>Yes <input type="checkbox"/>No</p> | <p>15. Been satisfied with the support my family has given me<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>16. Found my relative’s living situation to be inconvenient or a barrier to care<input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>17. On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful,” please rate your current level of stress. _____</p> <p>18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill,” please rate your current health compared to what it was this time last year. _____</p> <p>Comments:
<i>(Please feel free to comment or provide feedback)</i></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> |
|--|---|

Appendix II: Family Caregiver Alliance (FCA) Resources on Caregiver Assessment Available at www.caregiver.org

Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. I). San Francisco: Author.*

Reflects the professional consensus achieved at the National Consensus Development Conference *for* Caregiver Assessment: the importance to policy and practice of systematically assessing a caregiver's own needs in health care and in home and community settings; fundamental principles and practice guidelines for caregiver assessment applicable to a range of practitioners in a variety of settings; and strategies and actions to advance caregiver assessment as a basic component of practice. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf

Family Caregiver Alliance (2006). *Caregiver Assessment: Voices and Views from the Field. Report from a National Consensus Development Conference (Vol. II). San Francisco: Author.*

Provides two personal accounts of the family caregiving experience and four background papers on the topic of caregiver assessment from a research, practice, policy and international perspective. Together they portray key issues in caregiver assessment and illustrate the impact of caregiving at home on the family members who provide the care and support. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/v2_consensus.pdf

Family Caregiver Alliance (2002). *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners. San Francisco, CA: Author.*

Represents a select group of caregiver assessment measures specifically chosen for practical application by practitioners who work with family and informal caregivers of older persons and adults with disabilities. The purpose of the inventory is to provide a compendium of caregiver assessment measures that

is practice-oriented, practical and applicable, and which conceptually addresses the multidimensional aspects of the caregiving experience. The inventory compiles over 100 measures into a user-friendly table that is organized into six conceptual domains: positive and negative effects of caregiving, care tasks and skills, caregiver health, financial impact of caregiving, caregiver social support, and caregiver values and preferences. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/op_2002_resource_inventory.pdf

Feinberg, L.F. (2004). *The State of the Art: Caregiver Assessment in Practice Settings*. San Francisco, CA: Family Caregiver Alliance.

Summarizes the reasons for assessing family caregivers and identifies what, whom, when and where to assess. In addition, the monograph explores commonalities as well as differences in caregiver assessment instruments and points out areas of caregiver assessment that have been neglected. The report also discusses training issues for practitioners. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/op_2002_state_of_the_art.pdf

Feinberg, L.F., Newman, S., Gray, L., Kolb, K. & Fox-Grage, W. (2004). *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.

The first national study to examine publicly funded caregiver support programs throughout all 50 states. It focuses on caregiver support provided through the Older American Act's National Family Caregiver Support Program (NFCSP), Aged/Disabled Medicaid waiver programs, and state funded programs. The study found that about one-fourth of the states use a uniform assessment tool for all HCBS programs for the elderly and adults with disabilities. Systematic assessment of family caregivers was found to be a component in just five states' uniform assessment protocols. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/50_state_report_complete.pdf

Feinberg, L.F., & Newman, S. (2002). *Family Caregiver Support: Policies, Perceptions, and Practices in 10 States Since the Passage of the National Family Caregiver Support Program*. San Francisco, CA: Family Caregiver Alliance.

Describes the preliminary experiences of 10 states in providing support services to family or informal caregivers of the elderly and adults with

disabilities focusing on the National Family Caregiver Support Program, state general funds, Medicaid-waiver programs, and other state-funding streams. State and local implementation of caregiver assessment policies, tools and procedures under the NFCSP were found to be at very different stages. At the time, Pennsylvania and Florida were the only case-study states that utilized a consistent assessment instrument including a caregiver component for all HCBS programs. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/op_200211_10_state_full.pdf

Feinberg, L.F., Wolkwitz, K. & Goldstein, C. (2006). *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*. Washington, DC: AARP Public Policy Institute.

This report highlights three emerging trends that have important implications for addressing the needs of family caregivers: caregiver assessment; consumer direction in family caregiver support services; and collaborations between the aging network and the health care system, for example, in identifying family caregivers who may be at risk for their own health problems and emotional strain associated with the caregiving role. The report addresses barriers to conducting assessments of caregiver needs, new directions, and the outcomes or benefits of conducting caregiver assessments. Results suggest that the concept of a single, universal assessment tool for long-term care clients, including family caregivers, is gaining attention in a number of states. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/ip_2006_09_caregiver.pdf

Appendix III: Selected Annotated Bibliography for Caregiver Assessment

This annotated bibliography includes brief summaries of 48 publications (journal articles, book chapters, monographs) concerning the assessment of family and informal caregivers of older persons and adults with disabilities. The following references are provided for background information on the rationale for implementing caregiver assessment in care settings; the use of this approach to enhance practice; and the issues and challenges in assessing family care. Citations used in the bibliography were compiled from resources at FCA's National Center on Caregiving and Internet searches using the Medline/PubMed database.

Selection Criteria and Organization: Most publications included in this bibliography have a primary focus on caregiver assessment. Some, however, make a contribution through their secondary focus on this subject. For example, documents are included that focus on the general assessment of older adults but recommend assessing the family caregiver also. A vast research literature exists on specific measures to assess family caregivers. The citations here only include articles and reports which review multiple measures or conduct a meta-analysis of caregiver measures useful for caregiver assessment in a practice setting.

The bibliography is organized in three sections: (1) general literature on the topic; (2) reviews of caregiver measures; and (3) international literature on the topic of caregiver assessment.

As a “work in progress” this bibliography is not meant to represent an exhaustive collection of literature on this topic. If you would like to recommend additional citations for inclusion, please contact FCA's National Center on Caregiving at (800)445-8106 or info@caregiver.org.

General Literature on Caregiver Assessment

Bass, D. (2002). *Content and Implementation of a Caregiver Assessment. [Issue Brief]. Washington, D.C.: Administration on Aging.*

Provides tips for developing the content of a caregiver assessment as well as describes the procedures for implementing and responding to assessment information. The brief includes user-friendly tables which present a broad range of characteristics that might be considered for inclusion in caregiver assessment. Available online at: www.aoa.gov/prof/aoaprof/caregiver/careprof/proguidance/background/program_issues/Fin-Bass.pdf

Baxter, E. (2000). *Caregiver assessment: Learn about the caregiver, distinct from the person with dementia. Alzheimer's Care Quarterly, 1 (3), 62-70.*

Proposes areas of assessment related to the caregiver that can be gathered over time while carrying out the care plan for a person with dementia. A few of the key areas described include; identifying the caregiver's learning/communication style, determining the caregiver's understanding of dementia, assessing the caregiver's physical and emotional health, and establishing what coping strategies he/she utilizes. Each area described is intended to be conducted in addition to, not instead of, a traditional assessment of the person with dementia.

Berg-Weger, M., Rubio, D., & Tebb, S. (2001). *Strengths-based practice with family caregivers of the chronically ill: Qualitative insights. Families in Society, 82 (3), 263-272.*

Involving the family and care recipient in the assessment and planning process is stressed in this paper. Also addressed is the need to intervene early to assess caregiver needs, reframe education and utilization of services as a strength and resource for caregivers, stress the positive aspects of caregiving, and plan for future needs. Reframing of the caregiving experience is also emphasized. Available online at: www.alliance1.org/Publications/fis/FIS_PDFs/82-3PDFs/FIS82-3_Berg-Weger&.pdf

Berkman, B., Maramaldi, P., Breon, E., & Howe, J. (2002). Social work gerontological assessment revisited. *Journal of Gerontological Social Work*, 40 (1-2), 1-14.

Presents the evolution of assessment research and identifies critical assessment factors as they relate to changing social work practice and the country's changing health care environment. The authors highlight the importance of the informal caregiving network and assert the need for social workers to consider both the elderly person's biopsychosocial needs and the family's adapting and coping capacity.

Bogardus, S., Bradley, E., Williams, S., Maciejewski, P., Gallo, W. & Inouye, S. (2004). Achieving goals in geriatric assessment: Role of caregiver agreement and adherence to recommendations. *Journal of the American Geriatrics Society*, 52 (1), 99-105.

Argues for discussion of caregiver expectations, involving caregivers in a shared care plan from the beginning, and emphasizes the importance of communication between the clinicians, patients and caregivers to maximize goal attainment. This approach is consistent with the movement of patient and family-centered care.

Bradley, P. (2003). Family caregiver assessment – Essential for effective home health care. *Journal of Gerontological Nursing*, 29, 29-36.

Home care nurses collected data on 51 older family caregivers from their caseloads to assess their health. Approximately half of caregivers reported poor or fair health and almost a quarter required home health services themselves. The author concludes that in order for home health care to be effective, nurses serving the geriatric population need to conduct systematic family caregiver assessments to identify caregiver health needs that could impair their caregiving ability.

California Workgroup on Guidelines for Alzheimer's Disease Management. (2002). *Guidelines for Alzheimer's Disease Management*. Los Angeles, CA: Alzheimer's Association of Los Angeles, Riverside and San Bernadino Counties.

A general guide for the ongoing management of people with Alzheimer's disease. In addition to addressing the patient's condition, the guide

recommends the family caregiver's needs and risks be assessed and reassessed on a regular basis. The guide also suggests that physicians solicit and consider the input of family caregivers in treatment planning. Available online at: www.alzla.org/medical/FinalReport2002.pdf

Coon, D., Williams, M., Moore, R., Edgerly, S., Steinbach, C., Roth, S., Phillips, C., Nguyen, H., Dowling, G., Dunning, E., & Feigenbaum, L. (2004). The Northern California Chronic Care Network for Dementia. *Journal of the American Geriatrics Society, 52*, 150-156.

Describes the Northern California Chronic Care Network for Dementia's intervention model that provides coordinated care to individuals with dementia and their families. This model is grounded in the identification, assessment, and care management of those with dementia, as well as family caregiver information and support. The paper emphasizes the importance of ongoing care and intermittent assessment of caregivers because family needs for information, support, referrals, and education change over time.

Davis, L. (2001). Assessing functional ability in persons with dementia: Using family caregivers as informants. *Journal of Neuroscience Nursing, 33* (4), 194-202.

Explores factors that influence family caregiver assessments of functional abilities in older individuals with some degree of cognitive loss or impairment. The paper also presents suggestions for enhancing the accuracy and dependability of functional assessments by family informants. The author concludes that assessments are valuable in determining both the older persons' abilities as well as the family member's continuing ability to be a caregiver.

Etten, M. & Kosberg, J. (1989). The hospice caregiver assessment: A study of a case management tool for professional assistance. *The Gerontologist, 29* (1), 128-131.

The Hospice Caregiver Assessment Inventory was developed to identify the problems of those caring for dying patients. Findings revealed the problems of caregivers and suggested that they often need counseling and assistance prior to the death of their loved one, as well as following death. The authors

conclude that the systematic assessment of caregiver needs, and plans for caregiver assistance should be a major component in hospice care.

Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. I). San Francisco: Author.*

Reflects the professional consensus achieved at the National Consensus Development Conference *for* Caregiver Assessment: the importance to policy and practice of systematically assessing a caregiver's own needs in health care and in home and community settings; fundamental principles and practice guidelines for caregiver assessment applicable to a range of practitioners in a variety of settings; and strategies and actions to advance caregiver assessment as a basic component of practice. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf

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Feinberg, L.F., Wolkwitz, K. & Goldstein, C. (2006). *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support.* Washington, DC: AARP Public Policy Institute.

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strain associated with the caregiving role. The report addresses barriers to conducting assessments of caregiver needs, new directions, and the outcomes or benefits of conducting caregiver assessments. Results suggest that the concept of a single, universal assessment tool for long-term care clients, including family caregivers, is gaining attention in a number of states. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/ip_2006_09_caregiver.pdf

Fulmer, T., Firpo, A., Guadagno, L., Easter, T., Kahan, F., & Paris, B. (2003). Themes from a grounded theory analysis of elder neglect assessment by experts. *The Gerontologist*, 43 (5), 745-752.

Describes a program to screen for assessing for elder mistreatment and neglect. This program stresses the importance of understanding both the health status as well as the socioeconomic and life circumstances of the caregiving dyad. The authors conclude that future screening and assessment procedures should be developed with these themes in mind.

Gaugler, J., Kane, R., Kane, R., Clay, T. & Newcomer, R. (2003). Caregiving and institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, 43 (2), 219-229.

Identifies reliable predictors of nursing home entry among people with dementia, including caregiver burden and depression. The authors conclude that efforts to target at-risk older adults, particularly those with Alzheimer's disease, for community-based services may enjoy greater success and precision if indices of caregiver stress, burden, and caregiver physical well-being are incorporated into assessment tools.

Gitlin, L. & Gwyther, L. (2003). In-home interventions: Helping caregivers where they live. In D. Coon, D. Gallagher-Thompson & L. Thompson (Eds.), *Innovative Interventions to Reduce Dementia Caregiver Distress – A Clinical Guide* (139-160). New York, NY: Springer Publishing Company.

Includes a section on “Identifying Caregiver Needs” and offers different approaches to conducting family caregiver assessments. Also highlights the need for standardized assessments that can be used uniformly by service providers to elicit caregiver needs systematically.

Goetschius, S. (2001). Caring for families: The other patient in palliative care. In M. Matzo & D. Sherman (Eds.), *Palliative Care Nursing: Quality Care to the End of Life* (245-274), New York, NY: Springer Publishing.

Provides interventions and suggestions for palliative care for families. The author asserts that the fundamental principle of palliative care is that the patient and family together are the unit of care. Assessing the family as a system is the first step in developing a plan of care. Nurses must help family members identify what their *own* needs are in end-of-life care.

Kaye, L., Turner, W., Butler, S., Downey, R. & Cotton, A. (2003). Early intervention screening for family caregivers of older relatives in primary care practices – Establishing a community health service alliance in rural America. *Family and Community Health*, 26 (4), 319-328.

Describes the Maine Primary Partners in Caregiving project as an example of how community health, social service, and higher education institutions can build a successful rural service alliance for the purposes of screening for family members experiencing stress during the provision of care to impaired older relatives. The assessment measures caregiver well-being levels, including the degree of stress/burden, life satisfaction/morale, depression, confidence, competence/skill, quality of family relations and extent of social supports among caregivers.

Levine, C., Reinhard, S., Feinberg, L.F., Albert, S., & Hart, A. (2003-2004). Family caregivers on the job: Moving beyond ADLs and IADLs. *Generations*, 27 (4), 17-23.

Argues the need to change the current perception of caregivers as “the mirror image of the care recipient’s limitations.” By describing current approaches, or lack of approaches to caregiver assessment, the authors conclude that in addition to asking questions about their caregiving tasks and burdens, there is a need to ask caregivers to assess their own needs and emotional health.

Meilillo, K. & Futrell, M. (1995). A guide for assessing caregiver needs: Determining a health history database for family caregivers. *Nurse Practitioner*, 20 (5), 40-46.

Asserts that the failure to consider the psychosocial and health-related consequences of caregiving for individuals with dual roles could result in greater health care costs, jeopardize the health of the caregiver, and place the care recipient at risk of institutionalization. The article offers a guide that can be used as part of a comprehensive health history to assess the caregiving situation and provide a database on which to establish a plan of action. The caregiver assessment guide can be inserted in the client's health record and periodically reviewed during primary care visits.

Schwentor, D. & Brown, P. (1989). Assessment of families with a traumatically brain injured relative. *Cognitive Rehabilitation*, 7, 8-14.

Addresses the importance of a comprehensive family assessment in order to: 1) determine the extent the family can be involved in the patient's rehabilitation process and 2) to identify areas of family need for intervention and support. In addition, a comprehensive assessment process is outlined and various assessment methods are explained.

Vladeck, B. (2004). You can't get there from here: Dimensions of caregiving and dementias of policymaking. In C. Levine (Ed.), *Family Caregivers on the Job: Moving Beyond ADLs and IADLs* (123-137). New York, NY: United Hospital Fund.

Suggests the need for several basic public policies regarding the mandatory inclusion of caregiver assessments in the following areas: regular consultations between paid providers and informal caregivers, Medicare and Medicaid home care services, Medicaid home- and community-based waivers, and Medicare and JCAHO standards for hospital discharge planning.

Wright, L. & Leahey, M. (2005). *Nurses and Families – A Guide to Family Assessment and Intervention*. Fourth Ed. Philadelphia, PA: F.A. Davis Company.

With a clear focus on clinical nursing practice, this book promotes better family health care by providing educational tools and ideas for assessing the

needs of families. It offers clinical guidelines to assist families experiencing illness and to know when and how to intervene properly. Available online at: www.fadavis.com/related_resources/1_2021_683.pdf

Zwicker, D. & Picariello, G. (2003). Discharge planning for the older adult. In M. Mezey, T. Fulmer, I. Abraham, & D. Zwicker (Eds.) *Geriatric Nursing Protocols for Best Practice. Second Ed.* New York, NY: Springer Publishing Company.

Describes the assessment parameters for discharge planning in: functional status, cognition, depression, and caregiver support. The guideline specifically proposes that family caregivers be evaluated on a continual basis.

Reviews of Caregiver Measures

Antonucci, T., Sherman, A., & Vandewater, E. (1997). Measures of social support and caregiver burden. *Generations, 21* (1), 48-51.

Informs the reader about the personal and situational characteristics that should guide choices for an assessment instrument for older adults and their caregivers, including a conceptual and theoretical overview as well as a practical guide. The authors outline critical assessment issues unique to caregivers including social support and caregiver burden.

Deeken, J., Taylor, K., Mangan, P., Yabroff, R., & Ingham, J. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management, 26* (4), 922-953.

Identifies and critically evaluates 28 self-report instruments to assess informal caregivers. The instruments are identified and evaluated in terms of their development, content, and psychometric properties. Three user-friendly tables describe the instruments according to three categories; caregiver burden, caregiver needs, and quality of life instruments. A history of each construct and its measurement development are discussed.

Deimling, G. (1994). Caregiver functioning. In P. Lawton, & J. Terest (Eds.) *Annual Review of Gerontology and Geriatrics – Focus on Assessment Techniques (257-280)*. New York, NY: Springer Publishing Company.

Provides a broad overview of caregiver assessment measures and techniques by reviewing 15 caregiving specific measures of burden or strain. The measures are divided into two categories: caregiving effects and caregiver coping resources. In reviewing the measures, the original research that created the measures are described, the basic conceptual domains are identified and information on the measurement properties are provided.

Family Caregiver Alliance (2002). *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*. San Francisco, CA: Author.

Represents a select group of caregiver assessment measures specifically chosen for practical application by practitioners who work with family and informal caregivers of older persons and adults with disabilities. The purpose of the inventory is to provide a compendium of caregiver assessment measures that is practice-oriented, practical and applicable, and which conceptually addresses the multidimensional aspects of the caregiving experience. The inventory compiles more than 100 measures into a user-friendly table that is organized into six conceptual domains: positive and negative effects of caregiving, care tasks and skills, caregiver health, financial impact of caregiving, caregiver social support, and caregiver values and preferences. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/op_2002_resource_inventory.pdf

Gaugler, J., Kane, R., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. Kane & R. Kane (Eds.), *Assessing Older Persons – Measures, Meaning and Practical Applications (320-359)*. New York, NY: Oxford University Press.

Provides a review of 23 measures of the impact of family caregiving which are compiled into a user-friendly table. Measures are grouped into two categories, measures of burden and caregiving appraisals. A general description of each measure is provided as well as its method of administration and any potential limitations. In addition, the article includes sections on the rationale for assessing family caregivers, defining family caregivers, and conceptualizing the impact of caregiving.

Kinsella, G., Cooper, B., Picton, C., Murtagh, D. (1998). A review of the measurement of caregiver and family burden in palliative care. *Journal of Palliative Care*, 14 (2), 37-45.

Reviews issues in and methods of measurement of caregiver and family burden in the home-based palliative care of terminally ill patients. An overview is presented of burden measures that have been developed in palliative care research, including Caregiver Tasks, Caregiver Load Scale, Appraisal of Caregiving Scale, Caregiver Reaction Assessment, Caregiver Burden Tool, and the Modified Caregiver Appraisal Scale. Available online at: www.ircm.qc.ca/bioethique/francais/publications/JPC/echantillon/article6.pdf

Pearlin, L., Mullan, J., Semple, S. & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30 (5), 583-594.

Describes caregiver stress as a consequence of a process comprising a number of interrelated conditions, including the socioeconomic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed.

International Literature

Audit Commission (2004). *Support for Carers of Older People*. London, UK: Belmont Press.

Examines the nature and extent of the help that is currently available to carers in the UK and makes suggestions about how this can be improved. The report states that caregivers should be offered an assessment of their needs in order to “become real partners in the provision of care to the person they are looking after...” as the national strategy clearly sets out. Available online at: www.wales.nhs.uk/documents/OlderPeople_5_Report.pdf

Australian Institute of Health and Welfare (2004). *Carers in Australia: Assisting Frail Older People and People with a Disability*. Canberra, Australia: Author.

Aged Care Assessment Team guidelines require that the needs of carers are considered when making recommendations. Carers are an official target group

for home and community-care services and the most recent national data collection also indicate that the key role of carers is well recognized in the delivery of assessment and care services throughout Australia. Available online at: www.aihw.gov.au/publications/age/cia/cia-c00.pdf

Carradice, A., Shankland, M. C., & Beail, N. (2002). A qualitative study of the theoretical models used by UK health nurses to guide their assessments with family caregivers of people with dementia. *International Journal of Nursing Studies*, 39, 17-26.

Nurse education in the UK does not provide the training necessary to conduct a thorough and complete assessment of carers. This qualitative study suggested that nurses utilized the Stress Process Model to assess caregivers. Nurses underscored the importance of an open rapport with caregivers to establish a relationship that stresses listening to the caregiver, being empathetic, and allows caregivers to talk about their role. Findings suggest that nurses need additional training and education to understand the complexities of caregiver stress and thus guide assessment and intervention.

Fancey, P., Keefe, J. & Robertson, M.L. (1999). *Development of Screening and Assessment Tools for Family Caregivers – Phase I Report on Review of Non-Validated Tools – Nova Scotia Site. Ottawa, Canada: Health Transition Fund of Health Canada.*

An international review of 57 articles and reports referenced 63 validated and nonvalidated caregiver assessment tools. The research did not find any of the validated tools to address a range of caregiving issues or specific service needs of caregivers. The results of the review informed the development of the Canadian caregiver assessment and screening tool.

Guberman, N., Keefe, J., Fancey, P., Nahmiash, & Barylak, L. (2001). *Development of Screening and Assessment Tools for Family Caregivers. Ottawa, Canada: Health Transition Fund of Health Canada.*

Describes the methodology and results of a Canadian project to develop a screening and an assessment tool for assessing the context, conditions and the needs of family caregivers. An evaluation of these tools is described as well as the recommendations and policy implications of their implementation.

To facilitate future implementation, the authors suggest that these tools be integrated with existing assessment tools and that caregivers become an agency priority. Available online at: www.msvu.ca/Family&Gerontology/Project/healthCanada.pdf

Guberman, N., Nicholas, E., Nolan, M., Rembicki, Lundh, U., & Keefe, J. (2003). Impacts on practitioners of using research-based carer assesment tools: Experiences from the UK, Canada and Sweden, with insights from Australia. *Health and Social Care in the Community, 11 (4), 345-355.*

Describes the impact of three caregiver assessment tools from Canada, the UK and Sweden on the professional practice of assessors. The results reveal that the use of carer assessments can lead to changes in the adequacy and appropriateness of intervention to the service user. In addition, by giving carers a legitimate voice, acknowledging their perspective and expertise, practitioners can recognize them as individuals with their own needs and aspirations, rather than seeing them primarily as resources.

Larizgoitia, I. (2003). Evaluating long-term care – Approaches to evaluating LTC systems. In J. Brodsky, J. Habib & M. Hirschfeld (Eds.) *Key Policy Issues in Long-Term Care (227-242)*. Geneva, Switzerland: World Health Organization Collection on Long-Term Care.

Addresses many critical long-term care (LTC) issues including the role and support of family caregivers. Recommends that LTC coverage be based on an assessment of needs of the person requiring LTC as well as their informal caregivers in order to plan resource allocation. It also states the responsiveness to the legitimate expectations of persons requiring LTC and their informal caregivers must be translated into continued improvement of services.

MacLennan, W. J. (1998). Caring for carers. *Age and Ageing, 27 (5), 651-652.*

Argues for assessment, treatment, and care for carers in their own right. Education for health care practitioners about caregiving in general and how to support caregivers in particular is also stressed. The employment of a “family-care worker” is suggested. The goal of this worker is not only to support the care recipient, but also the needs of the whole family. Evidence suggests that

this approach improves the psychological and social well-being of both the caregiver and care recipient.

Montgomery, A. & Feinberg, L.F. (2003). *The Road to Recognition: International Review of Public Policies to Support Family and Informal Caregiving. Issue Brief. San Francisco, CA: Family Caregiver Alliance.*

Highlights where family caregivers stand in relation to public policies for long-term care. The six countries reviewed (Australia, Canada, Germany, Japan, United Kingdom and the United States) represent diverse philosophies and policies with regard to supporting and sustaining family care of frail elders and persons with disabilities. Included is a discussion of policy issues and approaches to caregiver assessment in the six countries. Available online at: www.caregiver.org/caregiver/jsp/content/pdfs/op_2003_the_road_to_recognition.pdf

Nankervis, J., Schofield, H., Herman, H. & Bloch, S. (1997). Home-based assessment for family carers: A preventative strategy to identify and meet service needs. *International Journal of Geriatric Psychiatry, 12, 193-201.*

Identifies unmet need for services among family carers and their frail or disabled relatives along with the factors associated with such needs through assessments of the carer/care recipient dyad. The authors conclude that assessment of elderly and other disabled adults should include their carers and systematically attend to carer needs, thus potentially enhancing morale, care management and access to a wider spectrum of services.

New Zealand Guidelines Group (2003). *Assessment Processes for Older People. Wellington, New Zealand: Author.*

These guidelines provide evidence-based recommendations for appropriate and effective assessment processes to identify personal, social, functional and clinical needs in older people. In addition, the guidelines recommend that carers of older people be assessed for health, training, and support needs with a specifically designed tool for carers that is linked with the assessment of older people. Available online at: www.guideline.gov/summary/summary.aspx?doc_id=4341&nbr=3274

Nicholas, E. (2003). An outcomes focus in carer assessment and review: Value and challenge. *British Journal of Social Work, 33, 31-47.*

Explores the benefits and challenges of implementing an outcomes approach to carer assessment and review, highlighted by a research and development project undertaken in partnership with one local authority. The project developed and tested research-based practice tools which aimed to promote carer-centered practice, together with clarity in communication and recording of outcomes intended and achieved. Findings indicated that practice could be enhanced with the help of a clear conceptual framework and tools, flexibly and sensitively used to assist discussion and decision-making with carers about outcomes.

Pierce, G. & Nankervis, J. (1998). *Putting Carers in the Picture: Improving the Focus on Carer Needs in Aged Care Assessment.* Melbourne, Australia: Carers Association Victoria.

Aims to encourage more emphasis on carer needs in aged care assessment and to help the service providers who work with and support carers. The study looks at carers' perspectives of their needs when being assessed and the formal and informal supports and interventions they need when caring.

UK Department of Health (2001). *A Practitioner's Guide to Carers' Assessments Under the Carer's and Disabled Children Act 2000.* London, UK: Author.

A good practice tool for practitioners carrying out assessments of adults caring for adults. The guide includes eligibility and access information, the purpose, process and content of an assessment as well as intended outcomes. Available online at: www.devon.gov.uk/contrast/practitionersguide-2.pdf



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