

Sustainable Care-giving: Maximizing Supports in Middle Phase Dementia Clinical Practice Recommendations

Introduction:

Ideally, when a client is diagnosed early, clients and families have time to evaluate their personal situation and make decisions. They need to talk together about preferences regarding who will provide care, what personal resources are available, how roles will change, who will assume these roles, and who will make substitute decisions when the individual with dementia is no longer capable of representing him or herself. However, all too commonly, circumstances don't match this ideal. Many clients and families may have not received an early diagnosis, or have been able to benefit from early psycho-social interventions such as these. They may not have had the opportunity to talk out a family plan, and by the middle phases of dementia, many caregivers find themselves struggling to cope and make sense of their situation which can easily deteriorate into crisis.

The dynamics of dementia care-giving are highly complex and variable. Which characteristics, knowledge and skills of the caregiver direct their interactions and lead to success? What is the best way to support the diverse needs of different caregivers? What are the characteristics of sustainable care-giving? This module examines what is known about the dynamics of care-giving in the middle phases of dementia and the types of supports and interventions necessary to work towards achieving a balance between client and caregiver needs that fosters sustainable care-giving.

What are the issues?

Regardless of the type of dementia, individuals in the middle phases generally experience enough loss in cognitive ability that they are increasingly dependent on their caregivers for basic daily living help. The resulting care-giving can be both an uncertain and stressful experience, but it can also be a very personal journey of discovery and unrealized potential^{1,2,3}.

“It's not a single event of care-giving... it's a marathon... and sometimes it seems to goes on forever” Janice, Caregiver

Anxiety. Exhaustion. Depression. These are emotional states that are experienced all too commonly by dementia caregivers. By the middle phases of dementia, caregivers often find themselves struggling to assume greater responsibilities, changing and additional roles^{55,56}, and are facing challenges as to how they can best meet the increasing dependence⁷ of the person with dementia for the most basic of daily needs. Personal reserve and capacity to provide such a high level of intimate care begins to thin, and the day-to-day living demands often take a toll on caregiver physical⁴ and mental health^{5, 6,22}. The health care system relies heavily on informal care (e.g., family) to meet the daily needs of persons with dementia. While the health care system can augment family efforts, it cannot replace or fully cover the care that is needed at home. Caregivers continue in their roles until the needs of the person with dementia exceed all capacity of their caregiver(s) and institutionalization is indicated.

* A recent longitudinal caregiver intervention study (Perren et al, 2006) suggests that it is not only the severity of current problems and stress, but also the rate of change, that affects caregivers' well-being.

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“I find myself appreciating my relationship with my mother in a new way. I’m learning new things about her everyday! For example, I’ve come to understand that the particular strengths that helped her cope with life’s ups and downs in the past are now sometimes at the root of our troubles. Oh, she can be so stubborn! But I need to figure out how to use this and not fight it.... Now more than ever, she needs me, and I want to be there for her”

Eleanor, Caregiver

There is an alternative side to care-giving, as well. Many caregivers are able to identify the personal growth, pride and positive benefits that care-giving has had on their relationship with the person with dementia. Interdisciplinary health providers can help caregivers gain perspective by providing a positive lens for caregivers to reframe their experiences and to ultimately feel positive about themselves and the care-giving experience. Endurance and perseverance in care-giving is possible when a balance is achieved between the needs of the person with dementia and the needs of the caregiver. Interdisciplinary health providers can help caregivers to see the value of learning the skills needed to self-manage and advocate for their own needs while still maintaining the role of primary caregiver⁷.

What is needed?

As much as possible, caregivers require both early and *ongoing* care-giving information and supports throughout the journey of dementia[†]. Research suggests that to sustain and support caregivers over time requires intervention efforts to be targeted to specific caregiver needs^{8,22,29} and that different interventions are needed at different stages of dementia^{9,10}. The types of intervention need to be matched to the client and family resources, strengths and abilities and identified needs^{11,12,29}. Sustainable care-giving is about developing a genuine, collaborative partnership with family caregivers in an effort to preserve personal health, enhance caregiver reserve, and provide options and choices that recharge and rekindle caregivers so that they may succeed and even grow as they carry out their care-giving commitments to the best of their abilities. How can one do this?

Targeting Effective Care-giver Interventions:

Sustainable care-giving requires targeting the right composite of support interventions and services to achieve real and perceived benefits for the individual caregiver. There are essentially two types of caregiver intervention: those that benefit the caregiver by augmenting their caregiver abilities (knowledge, skills, beliefs, coping strategies, sense of self-efficacy) and those that provide temporary or permanent relief of direct care-giving duties (respite options, housing change, facility admission).

a) Augmenting Caregiver Abilities:

Recent research indicates that a combined approach of *targeted skill-building with information* (rather than information-giving in isolation or the provision of broad-based, general interventions) and *psychosocial support* results in caregivers achieving a better understanding, and the insight and skill into the needs of the person they are caring for^{13,14,15}, as well as the emotional support that helps to relieve psychiatric distress such as depression and anxiety^{8,9,19,22}, and seeks to enhance the caregiver’s sense of self-efficacy^{16,17,18}

[†] Caregivers in the focus groups (Kelowna and Vernon, May and July 2006) identified they were either given no care-giving information upon diagnosis, or received an over abundance of information upon diagnosis. They described feeling overwhelmed, and having difficulty being able to “make sense of it”. Most participants stated they did not realize that the information, when given, may relate to the future (they were unable to distinguish this in the beginning). Caregivers highlighted their need to receive small, frequent amounts of pertinent information and knowledge over time, addressing specific knowledge needed at different stages.

i) Skill-Building Interventions:

Why is skill-building an important caregiver intervention? In recent skill-building intervention studies^(Error! Bookmark not defined.,13,14.), the emotional and physical toll of care-giving was much more apparent for less skilled caregivers than skilled caregivers. Of note is that skilled caregivers worked at integrating some aspects of self-care into their lives. Skilled caregivers were able to make connections between what was happening for the person they were caring for, their own feelings and responses, and their abilities to effectively manage their situations, whereas the knowledge, perceptions and behaviours of less skilled caregivers were much more limited in this capacity.

This small but growing body of research, as well as descriptions of caregiver's experiences from focus groups[‡] have been used to identify two priority areas in which caregiver knowledge and skills would benefit from a focus on skill-based interventions: 1) Skills related to providing direct care for the person with dementia; and 2) Skills related to addressing caregiver issues and concerns. The details of these skill sets are outlined in the recommendations of this module.

ii) Psychosocial Support Interventions:

Psychosocial support interventions (e.g., counselling, linkage and role coaching) are recommended to work in combination with skills training interventions to improve both the affective states and the type of coping strategies used by caregivers¹⁹. Three types of coping strategies have been identified in research^{20, 21}: 1) problem-solving (problem-focused coping to deal with changeable stressors), 2) reframing (emotion-focused coping to manage the emotional responses to unchangeable stressors), and 3) seeking social support (either problem or emotion-focused coping). In a recent systemic review of the efficacy of psychosocial interventions that reduce caregiver anxiety²², there is some evidence to indicate that strategies which target helping caregivers to manage the emotional and physical demands of caring may be more effective than strategies that target relieving direct caregiver duties (e.g., respite). This finding however needs to be considered carefully in context of what relief strategies are being offered, and whether delivery strategies result in barriers to use^{§,51} (e.g., multiple support workers assigned, etc.)

In summary, augmenting caregiver abilities requires health providers to work with caregivers to support long-term skill development and to build and enhance caregiver reserve through activities such as providing information, counselling, linkage and role coaching.

b) Caregiver Relief Interventions

Taking a break from the care-giving role is a pivotal point in sustainable care-giving. While a variety of health system services have been designed with the intent to bring caregiver relief, it is critical to remember that **respite is a caregiver outcome and not a specific service**. Community-based service programs offer caregiver relief of duties through such services as case management, adult day services, in-home respite and home support services, as well as options for short and long over-night respite outside of the home. Are these services effective? Evidence from caregiver research²³ and feedback from caregiver support groups indicate a mixed and variable result of these formal services.

[‡] Notes from participant comments during caregiver focus groups, conducted in Kelowna and Vernon in May and July 2006.

[§] See identified barriers to caregiver relief in Appendix A which were identified from the caregiver focus groups within Interior Health.

“Respite should be seen as the outcome derived by the caregiver as a result of being given either time off from care giving duties, or direct support for his/her needs... Respite is the break/time off/relief experienced by the caregiver, not the replacement service provided to the care recipient.” *Canadian Association for Community Care*

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Not everyone uses relief interventions, even when offered^{24,25,51}. Caregiver feedback from the IH focus groups indicates that there are frequent concerns with the lack of consistency of home support workers causing distress for the person with dementia and increasing the workload for the caregiver (“I have to re-explain everything all over again each time”). Lack of staff consistency has also resulted in a loss of trust that the system can support the person adequately in the caregivers absence (“They won’t know what to do, they don’t know him like I do”) Research corroborates these expressed fears and under-utilization of these resources is directly related to the delivery structure^{26, 27,28}.

What then works?

Research shows that multi-component programs²⁹ (care plans that utilize 2 or more relief services in adequate amounts) which offer a choice of options to caregivers and are structured to be flexible enough in delivery to meet **specific** caregiver needs are the most successful in achieving caregiver outcomes such as reduced perceptions of burden³⁰, reduced anxiety, reduced reports of stress and fatigue³¹. Relief interventions, such as adult day centre in combination with intensive case management and home support show that over time, there is an improvement in caregiver affect^{30,32}. There is however, no significant evidence that any of these relief interventions significantly delay institutionalization^{8,21,29}. There are mixed results regarding the direct benefit of relief interventions for the person with dementia, or that they are effective in altering the person’s care needs (e.g., improve behaviour) in the home³².

From Recommendations to Active Practice: Support Needed!

Implementing evidence-based clinical practice recommendations can only result in positive practice changes if there are adequate planning, organizational and administrative resources and support, including appropriate education and training. Successful system change requires that *education/training, program planning* and *information management* are aligned and compatible with the goals and efforts of direct care providers. In order to support frontline staff to successfully close the gap between best practice and current practice, managers, educators and program planners need to ensure the system supports needed to deliver care are in place.

This module highlights the need for interdisciplinary health providers to use current knowledge of the different dementias to target different interventions at different stages. In order to deliver effective psycho-social intervention for caregivers, they need to understand that the specific clinical courses of the various types of progressive dementias will determine the particular dementia journey that the caregiver is experiencing. For example, the episodic memory loss in middle phase Alzheimer Disease now reaches a stage that most individuals will now require supervision, cueing and sub-tasking for daily activities such as bathing, dressing and eating. Repetitive questions can challenge the most patient of caregivers. The person with AD needs frequent reassurance in a world that has lost meaning. This requires caregivers to adapt the home environment and to find meaningful activities. By contrast, individuals with fronto-temporal dementias (e.g., Pick’s disease) may still have their episodic memory relatively well preserved, but symptoms such as increased impulsivity, swearing, and hyperactivity that include outbursts and aggression, will require caregivers to not take such behaviours personally and to navigate challenging behaviours in the course of care-giving. For the client with Lewy-Body Dementia, the disease often progresses quite quickly as compared to Alzheimer Disease, so time-wise, the middle phases may occur much sooner. Commonly there are large daily fluctuations in confusion, visual hallucinations,

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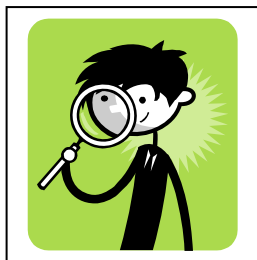
language abilities, and physical movement, resulting in a constantly changing care-giving environment which challenges these caregivers to provide the right amount and type of help at the right time and to do so without creating an excess of disability (taking over, doing for). Every experience is different. In summary, health providers need to be guided by their knowledge of specific dementias to better evaluate care-giver experiences, and they need ongoing, continuing education and clinical consultation resources to achieve this.

The Phased Dementia Pathway: Creating “Best Practice” in Early Phase Dementia Care:

The following Clinical Practice Recommendations were created as part of the IH Phased Dementia Pathway. These recommendations are evidence-informed or “best practice”, and were created by the process described in the IH Dementia Care website^{**}. Clinical Practice Recommendations at the Early Dementia phase of the pathway highlight the need for interdisciplinary health professionals to recognize early cognitive changes, including the potential for depression and delirium, understand the clinical and ethical challenges related to early diagnosis and disclosure, and provide information, emotional and skill-building supports for the client and caregiver during the uncertainty of this phase.

Levels of Evidence and Strength of Recommendations

The SORT research grading tool^{††} emphasizes client-oriented outcomes – outcomes that matter to clients and help them live longer or better lives, including reduced morbidity, mortality or symptoms, improved quality of life and lower cost of health care services. Levels of evidence are ranked “**1, 2, 3**” based on the validity (quality) of the study design. Where existing relevant guidelines were found, they are cited as “**G**” in the level of evidence. Strengths of recommendations (**A, B, C**) are based on grading the quantity and consistency of the body of evidence. Ratings are listed following each recommendation or group of recommendations as needed.



Qualitative Evidence

No comparable grading tool was found for qualitative research, however the well established criteria of *credibility, applicability (or fittingness), auditability and confirmability* are used. All four criteria must be met in order to be considered suitable evidence for practice recommendations. A designation of “Q” is given under level of evidence and source cited.

Levels of Evidence and Strength of Recommendations Taxonomy

Levels of Evidence are ranked 1-3 based on the validity (quality) of the study design.

- 1** = Good quality client-oriented evidence
- 2** = Limited quality client-oriented evidence
- 3** = Other evidence

Evidence-based Recommendations are rated as follows:

- A** = consistent and good quality client-oriented evidence;
- B** = inconsistent or limited-quality client-oriented evidence;
- C** = evidence lacking, more research needed; based on expert consensus/usual practice

^{††}Ebell MH, Siwek J, Weiss BD, Woolf SH, Susman J, Ewigman B, & Bowman M. Simplifying the language of evidence to improve patient care: Strength of Recommendation Taxonomy (SORT): A patient-centered approach to grading evidence in the medical literature. *The Journal of Family Practice* 2004;53(2):111-120, available in the public domain from <http://www.aafp.org/afp/20040201/548.pdf>

Clinical Practice Recommendations

The Dementia Clinical Practice Working Group advises the following clinical practice recommendations concerning the **assessment, referral, psycho-social support, skill-building and respite specific interventions for caregivers of persons with middle phase dementia.**

Provision of Care:

| <i>Interdisciplinary professionals in all sectors are encouraged to use the following practice recommendations to guide assessment, problem-solving, decision-making and all aspects of providing care to the caregivers of persons with middle phase dementia.</i> | Level of Evidence (sources cited) | SOR ^{††} |
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| <p>I. STRATEGIES THAT AUGMENT CAREGIVER ABILITIES:</p> <p>1. Recognition, Assessment and Support of Caregiver Psychosocial Needs:</p> <ul style="list-style-type: none"> • Caregiver needs require a respectful approach to assessment. This is best achieved when clinicians: <ul style="list-style-type: none"> ○ arrange private opportunities to speak with caregivers without the client being present; ○ seek to build a trusting and supportive relationship with caregivers over time; ○ listen carefully to the use of language and terminology used by caregivers and then use their preferred terms in discussion (e.g., “memory problems” vs. “dementia” or “Alzheimer disease”) • Holistic assessment of caregiver needs requires the clinician to: <ul style="list-style-type: none"> ○ use knowledge about the clinical course of specific dementias to make relevant inquiries aimed at identifying what the current issues and concerns are that the caregiver may be experiencing^{§§} (e.g., memory loss affecting ADL abilities, or losses in behavioural control leading to aggression, or language losses affecting self-expression, etc.). ○ assess the quantity and quality of the caregiver’s social network for both care-giving support and for opportunities for the individual to continue an independent social role outside of care-giving; ○ evaluate the change in family roles that the caregiver is currently experiencing, including, but not limited to: <ul style="list-style-type: none"> • the addition of roles previously carried out by the client • the availability and support from other family members in assuming previous client roles, or in providing respite to the primary caregiver; • the loss of caregiver secondary roles (often social, individual interest, hobbies, etc.) that | <p>3^{34,35,36,37}</p> <p>Meta-analysis²⁹ 3</p> <p>Q^(3,6,49,55)</p> <p>Q^(6,38,49,54,55)</p> | <p>B</p> <p>B</p> <p>B</p> <p>B</p> |

^{††} Strength of Recommendation

^{§§} In caregiver focus groups, caregivers did not always associate a client behaviour or loss in functional ability with disease, which sometimes led to misunderstandings, assuming the behaviour was done on purpose, or that the difficulty was within the client’s ability to change “if they wanted to” and the belief that the person was being difficult. Additionally, caregivers did not always identify or volunteer information about concerns unless specifically asked because they did not understand the relevance of the care issue to the clinical course of the dementia.

^{***} A score of >5 is suggestive of depression, a score of 10 or > almost always is depression.

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| <p>may be surrendered due to the demands of care-giving;</p> <ul style="list-style-type: none"> ○ regularly re-evaluate caregiver psycho-emotional and physical health status; ○ inquire into caregiver beliefs regarding their abilities to fulfill and continue in the care-giving role (self-efficacy) ○ prompt the caregiver to identify and evaluate self-care activities. <ul style="list-style-type: none"> ● Effective communication strategies when assessing caregiver needs require the clinician to: <ul style="list-style-type: none"> ○ listen carefully to caregiver reports of client mood, interest, functional indicators such as sleep or activity, etc, and any other behavioural and/or emotional changes as first line evidence regarding emotional state and coping abilities; ○ actively listen as to how caregivers are currently feeling about their care-giving roles; ● Strategies that assist caregivers to reframe their care-giving experiences in a balanced way require the clinician to: <ul style="list-style-type: none"> ○ make a balanced inquiry as to both the positive and negative aspects of care-giving; e.g., “Can you tell me about both what you think is going well and not so well in your care-giving?” ○ help the caregiver to identify positive coping strategies and clearly label examples of effective care-giving; ○ help the caregiver to identify and label areas of stress or uncertainty in their care-giving role and seek to identify what might be needed (information, support, skill-building, respite, etc) to address it; (see below) ● Sustainable care-giving requires assessment and monitoring for complications of care-giving, such as depression and anxiety. This requires clinicians to: <ul style="list-style-type: none"> ○ evaluate individual risk factors for caregiver depression and anxiety. These include, but are not limited to: <ul style="list-style-type: none"> ▪ historically poor relationship with client ▪ presence of client behavioural challenges ▪ emotional lability of the client ▪ increasing functional dependency of the client; ▪ long-term care-giving role ▪ loss or decline in social supports ▪ poor self-efficacy beliefs as a caregiver, etc ○ make decisions regarding the appropriate selection of, and approach to, using a standardized, validated screening tool for depression (e.g., GDS) if there is any clinical suspicion that depression may be present; | <p>3^(23,36,37,59,61,62)</p> <p>3^(37,59,61) Q^(7,14)</p> <p>1³⁹ 2^(5,40) Q System Review</p> <p>2^(16,17,18)</p> <p>2^(41,42) Guidelines⁴³</p> | <p>A</p> <p>B</p> <p>A</p> <p>B</p> |
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Phased Dementia Pathway –Middle Dementia Phase

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| <ul style="list-style-type: none"> ○ recognize the importance of referring caregivers to their physician for further evaluation when: <ul style="list-style-type: none"> ● there is clinical evidence of significant emotional strain, depression and/or evidence of poor/maladaptive coping. ● the caregiver scores greater than 5 on the GDS³³ (15-item geriatric depression scale)^{***} ○ understand the importance of monitoring reported emotional changes or difficulties over time to assess trends (improved, stabilized, decompensated). ○ provide the client and caregiver with local emotional support service information as required (e.g., individual counselling (e.g., mental health), caregiver support groups, local Alzheimer Society coordinator can be contacted through the Dementia Helpline) and encourage self-referral; | <p>Guidelines</p> <p>2^(6,10,11, 13) Q^(7,14)</p> <p>2^(20,31,26) 3^(23,59,61,62)</p> | <p>A</p> <p>A</p> <p>A</p> |
| <p>2. Assessment and Support of Information and Decision-Making Needs</p> <ul style="list-style-type: none"> ● Caregiver needs for information will change over time as the disease progresses. Information giving is not a one-time intervention. It is recommended that regardless of phase of dementia, clinicians regularly inquire as to what questions or information needs currently exist and address them promptly ● Clinicians need to assess the information needs of the caregiver by identifying: <ul style="list-style-type: none"> ○ what information they may have already received (and reinforcing as needed) ○ what questions or areas of concern they currently have as a result of care-giving; ○ what incorrect information or ideas they may be expressing; ○ what other areas of information may be required (e.g., for next stage or transition of care, etc.) ● In addition to verbal information during interview, clinicians should seek to provide appropriate written support material for caregivers to read in their own time and space, and to share with other family members or secondary caregivers. | <p>2^(10,11,12,13,31) Q^(13,14)</p> <p>Q^(13,14) 3^(51,57,61,62)</p> <p>Q</p> | <p>A</p> <p>B</p> <p>C</p> |
| <p>3. Targeting Skill-Building and Practical Problem-solving Needs for Caregivers:</p> <p>It is recommended that caregiver skill-building should focus on two main areas of interest:</p> <p>A) Skills related to providing direct care for the person with dementia; and</p> <p>B) Skills related to addressing caregiver issues and concerns.</p> <p><u>Note:</u> The following examples of effective care-giving skills can provide clinical direction for professional staff to target information, education and skill-building strategies for caregivers. Actual client/caregiver needs and abilities would guide the specific details of such interventions.</p> | <p>Q^(7,13,14) Meta-analysis²⁹ 2</p> | <p>A</p> |

††† Vigilance is a term that captures care-giving perceptions of their supervisory role in providing 24 hour care. Vigilant caregivers see themselves as “on duty” even when they are not “doing things”. Caregiver vigilance is not necessarily diminished when professional caregivers intervene or institutionalization occurs. Debriefing caregivers about their unique family care-giving knowledge and incorporating it into care-giving is a key strategy for nurses to use to build caregiver trust and reduce their vigilance time. (Mahoney, 2003).

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| <p>A) <u>Caregiver Skills needed to address care related issues for the person with dementia:</u></p> <p>1. <u>Caregiver skills needed to “deal with” cognitive decline:</u></p> <ul style="list-style-type: none"> ○ Acknowledging that “the disease” underlies major changes in the person with dementia; (e.g., it is not the fault of the person, and not to take behaviours as personally directed); ○ Responding to the person in a creative, flexible and emotionally responsive and respectful manner; ○ Developing vigilance skills (e.g., watchful supervision, protective intervening, anticipating, being there^{†††}) ○ Targeting the “right” (appropriate) level of assistance needed without promoting excess disability; ○ Seeking ways to preserve strengths and maintain involvement in meaningful activities and family life; ○ Monitoring their own (caregiver) emotional responses to the person’s needs. <p>2. <u>Care-giver skills need to effectively respond to the person’s ADL/IADL needs (direct care):</u></p> <ul style="list-style-type: none"> ○ Reading the person’s emotional, behavioural and physical cues for unfulfilled needs (e.g., restlessness, wandering, seeking); ○ Providing the right amount of assistance needed (variable from none to total, providing effective sub-tasking, cueing and direction, etc.); ○ Using a wide repertoire of interventions to respond to ADL/IADL needs based on historical knowing and understanding of the person’s interests, habits, preferences, etc. ○ Realizing that that their (caregiver) own responses (e.g., anger, overwhelmed, frustrated) will influence how successfully the person with dementia will or will not accept and receive care; ○ Knowing when to turn personal care needs over to another family member or professional (e.g., respite, complex care needs, caregiver strain); ○ Seeking opportunities to include the person to participate in simpler everyday tasks and activities (e.g., washing dishes, setting table, raking leaves) as one way to maintain the person’s strengths and involvement in family life; <p>3. <u>Care-giver skills that help address challenging behaviours and emotional responses:</u></p> <ul style="list-style-type: none"> ○ Recognizing that all behaviour has meaning. ○ Appreciating and acting on the knowledge that the person’s cognitive impairment, challenging behaviour, emotional responses and care environment result in complex and interactive relationships; ○ Attributing challenging behaviours to “the disease”, and not feeling the person is doing these | <p>Q^(7,14,48)</p> <p>Q⁴⁴</p> <p>Q⁴⁵</p> <p>†^(12,17,46,47) Q^(14,44,45, 48)</p> <p>Q^(14, 48,49) †^(12,17,19,46,47,48,50) Meta-analysis</p> | <p>A</p> <p>A</p> <p>A</p> |
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| <ul style="list-style-type: none"> things “on purpose”, or taking behaviours personally; ○ Acting on “behavioural sequences”, including understanding of what causes behaviours (triggers, consequences, feedback loops between caregiver and person with dementia); ○ Using a broad repertoire of interventions to respond to the person’s difficult behaviours and emotional responses (e.g., when one thing doesn’t work, then try another”) ○ Appreciating the person’s individual strengths and uniqueness despite dementia symptoms; ○ Using prescribed medications appropriately when behavioural and environmental interventions are no longer effective. | | |
| <p>B) <u>Caregiver Skills Required to Address Caregiver Issues and Concerns:</u></p> <ol style="list-style-type: none"> 1. Dealing with change <ul style="list-style-type: none"> ○ Acknowledging and accepting role changes brought about by care-giving; ○ Transforming negative attitudes into positive attitudes and experiences; ○ Being flexible in adapting life goals, lifestyle and living arrangements. 2. Managing competing Responsibilities and Stressors <ul style="list-style-type: none"> ○ Balancing personal, family and care-giving responsibilities; ○ Integrating ongoing life situations and care-giving into their life repertoire; ○ Using family relations as a source of strength and support; ○ Maintaining open communication with other family members; ○ Negotiating personal and family needs with caregiver requirements. 3. Providing a broad spectrum of care <ul style="list-style-type: none"> ○ Acknowledging the person’s strengths and working around their limitations (e.g., cues, prompts, sub-tasking, simplifying, role-modelling, redirecting, encouraging, etc); ○ Providing a broad range of behavioural interventions that augment retained abilities and support areas of loss (e.g., distraction, humour, diversion, etc) ○ Using medications appropriately when behavioural interventions are not effective; ○ Learning when to “draw the line” for the person with dementia and others safety (taking action when needed); ○ Providing the person with a safe, secure and emotionally supportive environment at home and within other social situations (e.g., maintaining routine, normalcy, preserving dignity, providing the “right amount” of supervision, etc); ○ Adapting positive activities for the person to participate in; ○ Setting realistic expectations and focusing on the process rather than the outcomes; | <p>Q^(7,11,14)</p> <p>Q^(7,14)</p> <p>Q^(7,14,44,45)</p> | <p>B</p> <p>B</p> <p>A</p> |

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| <ul style="list-style-type: none"> ○ Using assistive devices to promote safety and support for the person’s limitations (e.g., door locks, identification bracelets, hot water regulators, night lights, incontinence aids) <p>4. Finding and Using Resources:</p> <ul style="list-style-type: none"> ○ Being open to explore and educate self concerning available resources; ○ Accepting benefits that resources have to offer for both the person and themselves; ○ Being an assertive health care consumer; ○ Acknowledging and addressing one’s own emotional responses to the care-giving situation; ○ Developing collaborative relationships with health care professionals; ○ Knowing when to “draw the line” and accept professional help and/or consider facility placement. <p>5. Experiencing Emotional and Physical Responses to Care</p> <ul style="list-style-type: none"> ○ Balancing care-related and self-care activities; ○ Maintaining a personal flexibility in approaching life and caregiver demands; ○ Monitoring and creatively dealing with emotional responses to care-giving; ○ Implementing a regular plan of stress management; ○ Enlisting help from family and friends; ○ Maintaining healthy behaviours (e.g., eating, sleeping, exercise, activity); ○ Addressing own physical health concerns. | <p>Q^(14,40,44,48,50) 3^(51,57)</p> <p>1⁽¹⁹⁾ Q^(7,14,50) System Reviews^(8,9,21,22)</p> | <p>B</p> <p>A</p> |
| <p>II. STRATEGIES THAT PROVIDE RELIEF OF CAREGIVER BURDEN</p> <p>A. Assessment of Caregivers for Persons with Dementia: There is good evidence that an effective care approach for clients with dementia is to provide care to both the client and the caregiver as a pair (“dyad”). However, in fact, most current health systems do not formally recognize the caregiver as a recipient of care in their own right. This is best illustrated by the current common practice of providing respite related services through the formal assessment and care-planning of the person with dementia. Although the outcome of these services is specifically targeted for caregivers, the assessment</p> | | |

+++Caregiver assessment refers to a “systematic process of gathering information that describes a care giving 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”. ([Family Caregiver Alliance](#), 2006, page 12).

§§§ Note that not everyone identifies themselves as a “caregiver”, even when they are. On a number of occasions during the focus groups, caregivers denied the title of caregiver and described themselves within their relationship to the person with dementia, example, “I am her daughter, not her caregiver”. Care-giving was seen as an automatic and natural role within that family relationship, and several people were uncomfortable with the label of “caregiver”.

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| <p>of the caregiver is completed informally (e.g., they are not registered as a client and do not routinely or formally receive a systematic assessment, documentation and care-planning of their needs as separate from the person with dementia).</p> | | |
| <p>In the absence of system level policy and direction regarding formal caregiver assessment, support and care, the result is a sketchy and incomplete practice that ultimately rests with the experience and insight of individual clinicians. Establishing the caregiver as a recipient of care <i>in their own right</i> requires a fundamental shift in thinking and practice that requires system support. It starts with formal caregiver assessment as a basic component of dementia practice across care settings and over time.</p> | 3 ^(52,59,61,62) | |
| <p><u>The IH Dementia Clinical Practice Working Group makes the following clinical practice recommendations regarding assessment of caregivers for persons with dementia:</u></p> | | |
| <p>1. Caregivers of persons with dementia should be recognized and valued as requiring formal health care services (e.g., support and respite interventions) within their own right, as potential recipients of care.</p> | 3 ^(52,53,,59,61,62) | A |
| <p>2. Caregivers of persons with dementia should be receive regular, systematic and comprehensive assessment⁺⁺⁺ of their own physical, emotional, mental health, and care-giving related needs in a process that is separate from the person with dementia.</p> | 3 ^(52,59,61,62) | A |
| <p>3. Caregiver assessments should be offered to anyone who self-identifies^{\$\$\$} as a caregiver for a person with dementia. This inclusive approach recognizes that there may be more than one caregiver for a person with dementia and that the caregiver may or may not be a family member. Depending on the individual situation, caregiver assessments may be required for any or all of the following:</p> <ul style="list-style-type: none"> • primary caregivers (spouse, partner, daughter, son) • other family members (e.g., daughters-in-law) • friends or neighbours (e.g., when the person has no family and lives alone) | 3 | B |
| <p>4. The approach to caregiver assessment should be tailored to the individual caregiver situation and preferences. When the assessment involves the primary caregiver and one or more family members, the assessment may be conducted with individuals separately or with everyone together (e.g., family conference), if that is logically more feasible. Similarly, the caregiver should be consulted as to the presence or absence of the person with dementia during the caregiver assessment. An opportunity for privacy and to speak candidly should be routinely offered to the caregiver, including suggestions for alternate care arrangements for the person with dementia, if needed.</p> | 3 | B |

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| <p>5. Caregivers of persons with dementia should receive a comprehensive initial assessment, as well as follow-up assessments (to compare what has changed over time) on a regularly scheduled basis and/or as needed (example, following an acute episode that requires a change in care-giving).</p> | <p>3^(52,59,61,62)</p> | <p>A</p> |
| <p>6. Caregiver assessments should be provided across settings of care (home, hospital, residential care), but specific content areas and questions may be different, as may be the focus of services provided.</p> | <p>3^(57,61,62)</p> | <p>B</p> |
| <p>7. The assessment process allows caregivers to “tell their stories” and describe their unique care-giving situations. Interdisciplinary health providers should use knowledge of the different dementias and the specific clinical courses of the various types of progressive dementias to listen, probe, ask specific questions and guide the interview process so that they are better able to understand and empathize with the caregiver’s experiences.</p> | <p>Q^(54,55,56) 3^(37,57)</p> | <p>B</p> |
| <p>8. Interdisciplinary health providers should approach caregiver assessments that capture the following categories of information (See Appendix B for further detail):</p> <ul style="list-style-type: none"> ○ The background on the caregiver(s) and the care-giving situation ○ The caregivers’ perception of health and functional status of the person with dementia ○ The caregivers’ values and preferences with respect to everyday living and care provision ○ The health and well-being of the caregiver(s) ○ The consequences of care-giving on the caregiver(s) ○ The caregiver’s needs for skills, abilities and knowledge ○ The resources needed to support the caregiver. | <p>Q^(23,28,48) 2¹² 3^(37,57,59,61,62) Meta-analysis²⁹</p> | <p>A</p> |
| <p>9. Interdisciplinary health providers should receive education and support to enhance knowledge, abilities and skills needed to both assess and plan care for caregivers of persons with dementia. Key competencies include effective communication, involving the caregiver in decision-making, and being an effective advocate. See Appendix C for suggested educational topic areas.</p> | <p>3^(37,62)</p> | <p>A</p> |
| <p>B. Providing Respite Care for Caregivers of Persons with Dementia:</p> | | |
| <p>1. Interdisciplinary health providers should use the information provided by caregivers during assessment to identify concerns, problem solve and provide a plan care targeted to meet specific caregiver needs. Care-planning may include mutual goal setting (what does the caregiver want to happen?), referral, activation or coordination of social and system supports, or other multi-component interventions as required.</p> | <p>Q^(28,58) Meta-analysis 3</p> | <p>A</p> |
| <p>2. Respite services that provide mixed opportunities for both short and long breaks away from care-giving</p> | <p>2^(6,31)</p> | <p>B</p> |

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| <p>should be routinely and repeatedly offered to all caregivers for persons with dementia.</p> | <p>Meta-analysis²⁹</p> | |
| <p>3. Caregivers for persons with dementia should be given information about all the respite service options and choices available to encourage them to make informed choices.</p> | <p>3^{37,59}</p> | <p>A</p> |
| <p>4. Services that are selected to target caregiver burden (e.g., respite) should be provided in adequate amounts, with flexible options for caregiver choice on which tasks and activities would provide the greatest relief, and in a timely and responsive manner (e.g., when caregivers identify they need a break, optimally not a waitlist).</p> | <p>Q⁶⁰ 3^(6, 9,23,24,37,51)</p> | <p>A</p> |
| <p>5. Interdisciplinary providers should routinely assess both the caregiver and the person with dementia's response to respite services (e.g., following the initial set-up of service, or after several weeks), as well as the caregiver's post-respite adjustment back to the care-giving role after a longer period of relief.</p> | <p>2²³ Q^(28,32,54) Meta-analyses^(8,29)</p> | <p>A</p> |
| <p>6. Respite services tend to be designed and delivered in a standard "one size fits all" care approach, even though there are many different types of caregivers (cancer, chronic disease, frail elderly, dementia, etc.) with very different respite needs and concerns. Health care systems should routinely evaluate the effectiveness of existing respite services for caregivers of persons with dementia, including: eligibility, access, adequacy and type of resources (e.g., mixed short and long relief options), quantity, use patterns, flexibility (do caregivers have choice?), and person-centred (responsiveness to needs).</p> | <p>2²³ 3^(51,52,59,61)</p> | <p>B</p> |

Appendix A: Barriers to Caregiver Respite Use

In focus groups held in Interior Health for caregivers of persons with dementia, the caregivers describe several barriers to using respite services. These include, but are not limited to:

1. **The lack of consistent care-providers**. This was a major and repeated concern raised by caregivers. They reported that it impacted them in a number of different ways, including:
 - the need to repeatedly re-explain care needs in the home environment;
 - the lack of acceptance of new faces by the person with dementia
 - a real or perceived increase in anxiety and agitation of the person with dementia when the caregiver is no longer present, which in turn resulted in:
 - worry as to how the substitute caregiver will cope, especially with behavioural issues
 - the continued behavioural disruption for several hours even after caregiver return;
2. **System limitations** on what care and tasks providers can actually do within home environments;
3. **Complexity** of accessing the system;
4. **The need to ask**, rather than being offered;
5. **The short-lived nature of the relief** (a few hours), with the return to the care-giving role quickly erasing any positive benefit^{****};
6. **Perceived difficulty in leaving the person with dementia** (e.g., recognizing the need to get out of the care-giving role, giving themselves permission to get out and having the appropriate resources to do so)

^{****} Some members of the care-giver focus groups reported feelings of “let-down”, “a bit depressed” and “guilt” upon their resumption of care-giving following short respite. Qualitative research evidence indicates that caregiver responses to respite results in variable emotional and physical outcomes. The outcomes of a qualitative interpretative study of 20 caregivers (Strang, 2000) report caregivers that returned from short-term respite experienced despondency and emotional devastation upon return. Three factors that related to their experience were: 1) the amount of time and quality of the respite interval; 2) the nature and quality of the respite help that was used for the dependent family member; and 3) the condition of the person with dementia upon their return and resumption of the care-giving role. These factors influence the decision to use respite services.

Appendix B: Caregiver Assessments:

- While assessment approach can be tailored to the particular service setting or program, any caregiver assessment should:
 - Identify the primary caregiver and other family and friends who may be involved (in varying degrees) to arrange, coordinate or provide direct care for the person with dementia;
 - Approach issues from the caregiver’s perspective;
 - improve the caregivers’ understanding of their role and what they need to carry out tasks
 - give health providers the information needed 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 required.

- The following table outlines the areas to assess and provides some possible questions to seek this information^{††††}. The seven information categories, as outlined in the recommendations, arise from evidence-based content areas identified by experts⁶²

| Information Category | Areas to Assess | Possible Questions |
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| Background on the Caregiver and the Care-giving Situation | <ul style="list-style-type: none"> • Caregiver relationship to care recipient • Physical environment (home, facility) • Household status (number in the home, etc) • Financial status • Quality of family relationships • Duration of care-giving • Employment status (work/retired/home/other) • Financial status (e.g., ability to hire private respite or other help services) | <ul style="list-style-type: none"> • What is the caregiver’s relationship to the person with dementia? • How long has he/she been in the care-giving role? • Have they had previous care-giving experiences (parents?, etc.)? • Does the person with dementia live in the same household as the caregiver? • Is the caregiver married? Have children? How many people live in the caregivers’ household? • Are other family members or friends involved in providing care? What do they do and how often? • How would the caregiver rate his/her quality of family relationships? • Is the caregiver currently employed? Full-time or part-time? |
| Caregiver’s perception of Care-giving Role and Duties | The extent, frequency and types of care-giving duties of the care-giver role | <ul style="list-style-type: none"> • Can the person with dementia carryout ADLs /IADLs without assistance? how much assistance? how long does it typically |

^{††††} The following table was adapted with permission (rec’d Nov.21st, 2006) from the following original publication: Family Caregiver Alliance (2006). *Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers*. San Francisco: Author.
 N:\Dementia Resources\Middle Dementia Phase\Clinical Practice Recommendations v.2, 22 Sept. 2006, EA.

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| <p>based on the perceived needs of the person with dementia</p> | <p>over a 24 hour period for:</p> <ul style="list-style-type: none"> • Activities of Daily Living (ADLs) and need for supervision (level of supervision, cueing, etc.) ; • Instrumental Activities of Daily Living (IADL) • Psychosocial needs of the person with dementia • Behavioural challenges of the person with dementia • Medical care needs (drs. visits, tests, medications, etc.) of person with dementia • Other considerations as identified by the caregiver | <p>take? Does the caregiver feel confident and comfortable in providing this assistance? (have the necessary skills and knowledge?)</p> <ul style="list-style-type: none"> • Does the person with dementia have any emotional or behavioural challenges during the course of delivering care? How frequently do they occur? How much do they bother or upset the caregiver when this happens? • Can the person with dementia manage their own medical care needs? How much and how often do they require help? Has the caregiver been taught this knowledge and skills or did they just inherit the task(s) when the person with dementia was no longer capable? Is the caregiver comfortable and confident in providing this assistance? |
| <p>Caregiver Values and Preferences to everyday living and the need to provide care</p> | <ul style="list-style-type: none"> • Caregiver and person with dementia willingness to assume/accept care; • Perceived obligation to provide care (spousal, filial, etc.) • culturally based norms for care-giving (women’s work, etc.) • preferences for scheduling and delivery care and services. | <ul style="list-style-type: none"> • Is the caregiver willing to assume the caregiver role? • Is the person with dementia willing to accept care? • Does the caregiver feel he or she is obligated to provide care? • What types of care arrangements are considered culturally acceptable for this family? • What are the care-giver’s (and the person with dementia) preferences for the scheduling and delivery of care and services? (e.g., morning or bedtime routines) |
| <p>Health and Well-Being of the Caregiver</p> | <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 or her own health better, about the same, or worse than it was 6 months ago? • Does the caregiver have any health conditions or symptoms? Are there any identified conditions that impact or limit care-giving abilities, or that may in turn be affected by care-giving duties? For example, arthritis and the need to provide physical assistance in transfers from bed or chair) • How often in the past 6 months has the caregiver had a medical exam or received treatment for physical health problems from a |

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| | | <p>health care practitioner?</p> <ul style="list-style-type: none"> • Depression Screen: GDS-15 recommended • How often does the caregiver feel anxious or angry when she/he is around the person with dementia? • How often does the caregiver get a full night of uninterrupted sleep? • How does the caregiver rate his/her life satisfaction and/or quality of life? |
| <p>Consequences of Care-giving on the Caregiver</p> | <ul style="list-style-type: none"> • <u>Perceived Challenges:</u> <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><u>Perceived benefits:</u></p> <ul style="list-style-type: none"> ○ Satisfaction of helping person with dementia; ○ developing new skills and competencies ○ improved family relationships | <p><u>Perceived Challenges:</u></p> <ul style="list-style-type: none"> • Does the caregiver have a social support network or is she/he isolated? • Does the caregiver suffer any work-related difficulties due to the care-giving role? • Does the caregiver suffer from any emotional and/or physical health problems as a result of care-giving? (i.e., arthritis and lifting) • How much does the caregiver's health stand in the way of doing things that she or he wants to do? • What has been the financial strain, if any, on the caregiver due to his/her care-giving role? (e.g., early-onset dementia, loss of work) • How much disagreement has the caregiver experienced with other family members over particular care issues? <p><u>Perceived benefits:</u></p> <ul style="list-style-type: none"> • Does the caregiver feel satisfaction in helping the person with dementia? • Does the caregiver feel she/he has developed new skills and knowledge as a result of care-giving? • Has there been an improvement in family relationships (general closeness, communication, similarity of views, degree of getting along and helping each other out) as a result of the care-giving situation? |

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| <p>Caregiver Skills/Abilities and Knowledge to Provide Care</p> | <ul style="list-style-type: none"> • Care-giving confidence and competencies • Appropriate knowledge of dementia-related care needs (see pgs. 9-10 of this module for details) • Appropriate knowledge of medical care tasks (medications, ostomy, wound care, etc) | <ul style="list-style-type: none"> • How knowledgeable does the caregiver feel about the person with dementia's condition? • What are the skills and abilities needed to provide care for the person with dementia? • How would the caregiver rate her/his confidence and competence in these areas? • Does the caregiver have appropriate knowledge of medical care tasks and direct care tasks (e.g., transfer techniques to move out of bed to chair, etc.) |
| <p>Resources to support the Caregiver</p> | <ul style="list-style-type: none"> • Helping Network and perceived social supports • Existing or potential strengths (e.g., what is presently going well) • coping strategies (e.g., emotional vs. problem solving) • community resources and services (e.g., caregiver support programs, religious organizations, volunteer agencies) • financial resources (Veterans Affairs? Disability Pension?) | <ul style="list-style-type: none"> • Can the caregiver rely on his or her social support network for help? (e.g., respite) How much? how often? • What are the caregiver's coping strategies? Are these healthy/constructive? • What other community resources/services is the caregiver using or aware of (e.g., support groups, religious organizations?) • Has the caregiver accessed all financial benefits and entitlements that he/she (or the person with dementia) is eligible for? |

Appendix C: **Knowledge, Abilities and Skills Needed by Interdisciplinary Health Providers for Assessing the Caregivers of Persons with Dementia**

Knowledge about....

- Purpose of the assessment
- Self-determination versus safety issues
- Mental health, aging, life-course 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 caregiver 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 for people that may not be asking for help
- Disseminating information clearly, appropriately and as needed to connect to the care plan.

Source: Adapted from the Family Caregiver Alliance, “*Caregivers Count, Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers*” (2006), available at: <http://caregiver.org/caregiver/jsp/publications.jsp?nodeid=345&expandnodeid=463>

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