

After the Diagnosis: Supporting Client and Caregiver Needs at Home **Clinical Practice Recommendations**

The Pathway from Diagnosis to Living Well with Dementia: Identifying Clinical Issues

Following diagnosis and disclosure of early dementia, clients and their caregivers often experience multiple and competing care needs^{1,2}. This period is marked by several client and caregiver transitions: psycho-emotional adjustment to the diagnosis, shifting client abilities that may result in losses (and transfers) of long established family and social roles and identities, losses in self esteem and confidence, as well as the gradual decline in executive function that is so necessary to ultimately maintaining adult independence. Throughout this early phase, both the client and the caregiver will require *psycho-emotional support* and *informational needs*, and caregivers in particular will require *practical problem-solving and skill-building support* in their home environment as clients increasingly experience cognitive, mood, and behavioural disturbances that affect functional, social and relational abilities. In order to provide effective care and services for clients and caregivers in the early phase, health providers need to have a good understanding and appreciation for the needs and issues facing this client group.

Emotional support needs

Following the diagnosis and disclosure of early dementia, clients and caregivers are challenged to emotionally and mentally adjust to the new diagnosis of dementia, as well as understand the longer term implications it poses for the individual, caregiver and family³. Feedback from client and caregiver focus groups held in Interior Health* indicate that this period is initially hallmarked by emotional fragility and turmoil, with fear, anger, denial, anxiety and depression being commonly reported experiences. The research literature confirms these reactions, citing the commonest client reactions are fear^{4,5} (of others finding out, social embarrassment, dependency, not being listened to), anxiety⁵ (uncertainty of diagnosis, change in family and social roles, skill loss), loss of self confidence^{4,5} and depression^{6,7,8}. The qualitative literature also reveals a wide variety of themes in understanding, coping and adjustment strategies which corroborate descriptions of personal experiences from focus group participants. Thematic examples include “it will get worse” (demonstrating understanding), “I want to be me” (need to maintain identity⁹), “being unsure” vs. “trying to be normal”¹⁰, attempting to hide memory lapses from others and socially withdrawing vs. “going public” with diagnosis. Qualitative research indicates that strategies and stages of learning to live with early dementia change as the individual’s awareness of themselves and their outer world changes¹¹.

Additionally, although most health professionals understand and recognize the significant burden of dementia care-giving, it is important to note that the stress of care-giving begins very early. Focal group caregivers^(*,††) for individuals diagnosed with Mild Cognitive Impairment and various dementias in the early stages, report increased feelings of anxiety and depression, and were clearly able to articulate what and how they have had to adjust to changes in their loved one’s abilities. The significance of

* Based on focus group discussions with the Kelowna and Vernon Early Dementia Client and Caregiver Support Groups held in June 2005, April 2006 and July 2006, as well as ongoing interdisciplinary clinical focus group discussions throughout the term of the IH Phased Dementia Project.

caregiver burden starting this early in dementia is confirmed in recent research¹⁴. Understanding both the client and caregiver experiences and reactions can assist care providers to identify key areas in which earlier interventions may promote more adaptive coping strategies^{12,13,14}.

Information support needs

Following diagnosis, clients and caregivers need information to assist understanding, decision-making, and most of all, provide hope. Health professionals need to make decisions regarding the type, amount, order and method of information to provide, and employ strategies to avoid clients and caregivers becoming overloaded¹⁵. Adequate information should not only include issues considered relevant by clinicians, but should be tailored to the individual information needs of the clients and their caregivers¹⁶. Focus group feedback* indicates clients and caregivers seek basic information to understand symptoms, treatment options (particularly medications), and health system information, (particularly regarding care structures and access to services). Research indicates that the type of information sought by clients and caregivers changes with progression of disease¹⁷. Research also shows that most caregivers wish to receive information from a health professional, backed-up with written materials¹⁵.

Skill-Building and Practical Problem-solving Support Needs

More recent intervention studies indicate that caregiver skill-building interventions maybe more effective than information/support interventions alone^{18,19}. Research indicates that caregivers require skill-building support to address both client-focused issues, (such as practical problem solving for difficult behaviours and emotional responses, ADL and IADL challenges), as well as their own areas of concern (such as dealing with change, managing competing responsibilities and stressors, and experiencing emotional and physical responses to care).

Conclusion

Clients and families who have received a diagnosis of early stage dementia require emotional, informational and practical skill-building and problem-solving supports by interdisciplinary staff to help adjust and attain the best possible quality of life at home.

Creating Interdisciplinary Practice Recommendations to address Clinical Issues in the Early Phases of Dementia

The *Early Dementia Phase* of the pathway highlights the need for interdisciplinary health professionals to recognize early cognitive-related changes and related patterns of help-seeking, assist clients and caregivers to experience a smooth pathway to diagnosis by providing accurate timely information, referral and psychosocial support, and to provide post-diagnostic support (emotional, informational and skill-building/problem-solving) that optimizes client abilities and family resources to live well with dementia. The following Clinical Practice Recommendations are the second of three created to address these early phase issues. The IH Phased Dementia Pathway recommendations are evidence-informed or “best practice”, and were created by the process described in the IH Dementia Care website[†].

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.



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

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.

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 work towards ensuring the system supports required to implement Provision of Care Recommendations are in place.

[‡] 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>

The IH Dementia Clinical Practice Working Group advises the following Provision of Care practice recommendations concerning ***interdisciplinary support of client and caregiver emotional, informational and skill-building/problem-solving support needs following the diagnosis of early 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 care-giving for clients diagnosed with early dementia, as well as their caregiver(s).</i>	Level of Evidence (sources cited)	SOR [§]
<p>1. Recognition, Assessment and Support of Emotional Needs:</p> <ul style="list-style-type: none"> • The emotional support needs of both the client and the caregiver require careful assessment. This is best achieved when clinicians: <ul style="list-style-type: none"> ○ state upfront that the interview process will require there be opportunities to speak with the client and caregiver together, as well as privately with each; ○ When interviewed together, address the client directly and let them speak for themselves whenever and wherever possible (respectful caring). ○ listen carefully to the use of language and terminology and use the clients and caregivers preferred terms in discussion (e.g., “memory problems” vs “dementia” or “Alzheimer disease”) ○ use knowledge about the common emotional reactions and coping strategies following diagnosis to inquire about how clients and caregivers are currently feeling and coping with the diagnosis. ○ listen carefully to client and <i>especially</i> collateral (e.g., caregiver) reports of mood, interest, functional indicators such as sleep or activity, etc, and any other behavioral and/or emotional changes as first line evidence regarding emotional state and coping abilities; ○ evaluate known risk factors for caregiver and client depression (e.g., historically poor relationships, presence of behavioural challenges, emotional lability of the client, functional dependency, etc.); ○ make decisions regarding the appropriate selection of, and approach to, using a standardized, validated screening tool for depression^{**} in the elderly if there is any clinical suspicion that depression may be present; 	<p style="text-align: center;">Q²⁰ 3^(group consensus) 3²¹</p> <p style="text-align: center;">Q^(1,2,9,10,11,12,13)</p> <p style="text-align: center;">Guidelines²²</p> <p style="text-align: center;">2^(23,24)</p> <p style="text-align: center;">2^(25, 26)</p>	<p style="text-align: center;">C</p> <p style="text-align: center;">A</p> <p style="text-align: center;">A</p> <p style="text-align: center;">B</p> <p style="text-align: center;">A</p>

[§] Strength of Recommendation

^{**} The suggested tool for screening for elderly depression in dementia is the [Geriatric Depression Scale](#) (short form)

^{††} A highly recommended support resource is the [“Memory Problems?”](#) booklet from the Alzheimer Society. This booklet was written by the Early Stage Support Groups in the North/Central Okanagan Region of the Alzheimer Society of BC, created by people with dementia for people with dementia.

<ul style="list-style-type: none"> ○ recognize the importance of referring clients 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 client (or caregiver) scores greater than 5 on the GDS (short) ○ understand the importance of monitoring reported emotional changes or difficulties over time to assess trends (improving, stabilized, decompensating). ○ provide the client and caregiver with local emotional support service information as required (e.g., support group, local Alzheimer Society coordinator can be contacted through the Dementia Helpline) and encourage self-referral; ○ Provide appropriate written support material^{††} for clients to take away to read (or be read to if needed) in their own time and space. 	<p>Guidelines²²</p> <p>Q^(15,16,18,19)</p>	<p>A</p> <p>B</p>
<p>2. Assessment and Decision-Making Support of Information Needs</p> <ul style="list-style-type: none"> ● Assess information needs of both the client and caregiver by identifying: <ul style="list-style-type: none"> ○ what information they may have already received from their physician; ○ what questions or areas of concern they have; ○ what incorrect information or ideas they may be expressing; ○ what other areas of information may be required (e.g., for care, advanced planning, etc.) ● Identify and prioritize the information that is required. Research indicates that giving small frequent sources of information is better than providing a large amount of information at once. Although the type and amount of information needs to be uniquely tailored for individual client and caregiver needs, a general rule of thumb is to provide 3 areas or pieces of information at a time. Some research¹⁵ suggests information be given in the following order: <ol style="list-style-type: none"> 1. <u>General Information to be told at time of diagnosis</u> <ul style="list-style-type: none"> ● basic disease information following diagnosis; ● basic information about common emotional reactions; ● treatment and support options: <ul style="list-style-type: none"> ● non-pharmaceutical options (behavioural/ & environmental management); ● pharmaceutical options; 2. <u>Client-Focused information needs</u> <ul style="list-style-type: none"> ● information about cognitive decline (progression of disease) ● information about behavioural and psychiatric symptoms of dementia; 	<p>Q^{18,19}</p> <p>Q^(15,16,18,19)</p>  <p>Q^{15,16,18,19}</p>	<p>B</p> <p>B</p> <p>B</p>

<ul style="list-style-type: none"> information on practical problem-solving the challenges of everyday care (personal and instrumental activities of daily living); <p>3. <u>Caregiver-Focused information needs</u></p> <ul style="list-style-type: none"> information about legal and financial issues; (advanced planning) information about emotional and physical effects of caregiving; information on finding, accessing and using support resources <ul style="list-style-type: none"> Client and caregiver needs for information 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. 	<p>Q^(1,11,12,13,19)</p> <p>Q^(15,16,18,19)</p>	<p>A</p> <p>B</p>
<p>3. Assessment and Promotion of Skill-Building and Practical Problem-solving Needs for Caregivers:</p> <p>Recent research indicates that <u>targeted skill-building with information</u> rather than information-giving in isolation or the provision of broad-based, general interventions results in caregivers achieving enhanced understanding, insight and skill into the needs of the person they are caring for. More effective care, less stress experienced by the caregiver and the person they are caring for, as well as improved caregiver reserve are some of the significant outcomes from such skill-building interventions.</p> <p>In these studies, 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. Therefore, building caregiver abilities and reserve by supporting long-term skill development becomes the goal of skill-based intervention.</p> <p>This small but growing body of research, as well as descriptions of caregiver’s experiences from focus groups^{‡‡} have been used to identify priority areas in which caregiver knowledge and skills would benefit from skill-based interventions. Suggested areas in which caregiver skill-building should focus includes 2 main areas of interest:</p>	<p>Q^(18,19, 27)</p> <p>1^(28,29,30,31,32)</p> <p>1^(28,29,30,31)</p> <p>2^(18,19,33)</p>	<p>A</p> <p>A</p>

^{‡‡} Notes from participant comments during caregiver focus groups, conducted in Kelowna and Vernon in May and July 2006.

- A) Skills related to providing direct care for the person with dementia; and
- B) Skills related to addressing caregiver issues and concerns.

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.

A) Caregiver Skills needed to address care related issues for the person with dementia:

1. Caregiver skills needed to “deal with” cognitive decline:

- 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);
- Seek help and obtain a medical diagnosis as early as possible in the disease process (e.g., when changes are first recognized);
- Responding to the person in a creative, flexible and emotionally responsive and respectful manner;
- 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.

Q^(18, 19,33)

A

2. Care-giver skills need to effectively respond to the person’s ADL/IADL needs (direct care):

- 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 the caregiver 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

1^(28,29,30,31)

A

<p>activities (e.g., washing dishes, setting table, raking leaves) as one way to maintain the person’s strengths and involvement in family life;</p> <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 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”) ○ Appreciate the person’s individual strengths and uniqueness despite dementia symptoms; ○ Use prescribed medications appropriately when behavioural and environmental interventions are no longer effective. 	<p>2³⁴ Q^(9,10,12,14, 18,19) 1^(28,29,30,31,32,34)</p>	<p>A</p>
<p>B) <u>Caregiver Skills Required to Address Caregiver issues and concerns:</u></p> <p>1. Dealing with change</p> <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. <p>2. Managing competing Responsibilities and Stressors</p> <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. <p>3. Providing a broad spectrum of care</p> <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); 	<p>Q^(18,19,33)</p> <p>Q^(18,19,33)</p> <p>Q^(18,19,33)</p>	<p>B</p> <p>B</p> <p>B</p>

<ul style="list-style-type: none"> ○ 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; ○ 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^(13,14,2319,23)</p> <p>1⁽³²⁾. Q^(19,33,34)</p>	<p>B</p> <p>A</p>
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Clinically significant outcomes that may result from implementation of these recommendations include:

- relative client wellness (lack of depression, behavioural stability, active participation in daily life to best of abilities.
- reduction and management of psychiatric symptomatology (e.g., successful treatment of major or minor depression)
- general evidence of client and caregiver “living well with dementia”. (coping style and coping strategies reflect healthy lifestyle choices)
- caregiver satisfaction with services;
- appropriate service utilization;
- delays in institutionalization;
- improved communication, trust and partnership between caregiver and health care professionals.

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