

Phased Dementia Pathway – Early Dementia Phase

Supporting Help-Seeking Behaviours: The Pathway from Recognition to Diagnosis
Clinical Practice Recommendations

The Pathway from Recognition to Diagnosis: Identifying Clinical Issues

Feedback from client, caregiver and clinical (interdisciplinary) focus groups held in Interior Health* indicate that there are often difficulties and delays in the early recognition, referral and diagnosis of clients with dementia. Clients reported variable self-awareness into the symptoms and events leading up to diagnosis. Many caregivers reported that they “slowly became aware” of changes in their loved one, but found they were uncertain as to the meaning of the changes they witnessed and were not sure about when and to whom to initially seek help. Attempts to seek professional help were met with variable responses, ranging from satisfactory to adverse events, resulting in further delay.

Community and mental health clinicians report that they frequently first receive referrals or become aware of clients with dementia only in the mid-to-later stages of disease progression. Often by that time, there are considerable cognitive and functional losses, challenging behaviours and significant caregiver stress and burden. As well, reports of presentation to emergency (e.g., for a co-morbid condition or as a result of an accident) results in a *crisis pathway* that may lead to a formal diagnosis of dementia. Many professionals commented that it would be helpful to see clients and their caregivers at a much earlier phase of dementia, but that interdisciplinary linkages and current patterns of communication within the health system do not support interdisciplinary recognition, referral and diagnosis of early phase dementia clients.

A review of the research literature and other evidence echoes these focus group findings, and sheds a bit of light on some of the challenges and barriers that result in adverse pathways to diagnosis. First, in the early stages of the various dementias, particularly in fronto-temporal dementia (FTD)^{1,2} and Alzheimer disease (AD)^{3,4}, there is a significant erosion of self-awareness into multiple social, cognitive and emotional domains (e.g., behavioural unawareness, lack of self knowledge) on behalf of the client. Unlike clients with MCI, these clients are far less likely to self-report concerns about memory or other losses. Therefore, in early phases of dementia, it is usually close family members (particularly those who live with the client) who are more likely to recognize something ‘amiss’, and initiate help-seeking^{5,6}.

Second, early recognition of symptoms and initiation of help-seeking behaviours by family members appears to be a function of their overall knowledge of the symptoms of cognitive-related changes (such as symptoms of Alzheimer disease[†]), or recognition that a change in behaviour, language or judgement was serious enough to require medical investigation⁷. For those IH families that sought help, many reported that they were told the earliest symptoms of their concern were part of “getting older”. This resulted in *fragmented pathways* in help-seeking, and longer delays in diagnosis. Research evidence indicates a considerable lag between the caregiver’s first recognition of symptoms and initial attempts to seek help (up to one year), and an even further lag between first attempts to seek help and successful attainment of a formal diagnosis (another year to 18 months)^{8,9,10}. Finally, for a significant proportion of families (up to 21% in some reports), the pathway to diagnosis is a *dead-end* and no formal diagnosis is attained. These families are often characterized with significant language and educational barriers, as well as alternate beliefs and understanding of dementia that may be culturally based^{8,11,12}

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

† Cognitive impairment carries a social stigma in Canadian society, and stigma is a significant deterrent to seeking early diagnoses and care. Health Authority managers and program planners are encouraged to engage in opportunities to partner with local Alzheimer Society offices in efforts to raise public awareness, and provide early information and positive public messaging which may assist in reducing social stigma, enhance public knowledge, and promote acceptance of cognitive loss associated with Alzheimer Disease and related dementias (ADRD).

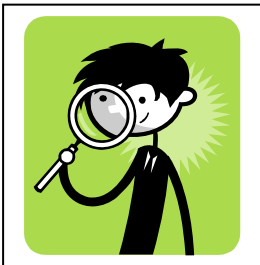
Conclusion: The clinical implications for clients and families who experience delays to diagnosis include delayed or lost opportunities for: 1) earlier treatment that may improve functioning; 2) participation in legal, financial and personal planning and decision-making about their future; and 3) the opportunity for both client and caregiver to emotionally adjust to the diagnosis and educate themselves about the road ahead.

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 that optimizes client abilities and family resources to promote independence and quality of life at home for both clients and caregivers. The following Clinical Practice Recommendations are the first of two 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.

[§] 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>

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.

The IH Dementia Clinical Practice Working Group advises the following Provision of Care practice recommendations concerning ***interdisciplinary support of client and caregiver help-seeking behaviours along various pathways that lead from early recognition of cognitive-related changes to the formal diagnosis and disclosure 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 all aspects of direct care related to clients with cognitive-related changes leading to a diagnosis of early dementia, as well as provide care to their family and or caregiver(s).</i>	Level of Evidence (sources cited)	SOR**
<p>1. Recognition and Assessment of cognitive-related changes:</p> <ul style="list-style-type: none"> • While there is insufficient evidence to recommend for or against routine screening for cognitive losses in older adults, it is recommended that interdisciplinary professionals develop an index of suspicion for cognitive changes, and use “opportunistic recognition” of cognitive loss during routine care assessments as a means of promoting early detection and referral for follow-up investigation. • Assessment of cognitive function requires interdisciplinary professionals to: <ul style="list-style-type: none"> ○ use knowledge about the continuum of cognitive-related changes, including normal aging, dementing disorders, delirium and depression to guide appropriate cognitive assessment; ○ evaluate clinical data such as observed declines over time in cognition, function (complex ADL and IADL), behaviour, or mood as key clinical indicators of cognitive- related change. ○ listen carefully to client and <i>especially</i> collateral (e.g., caregiver) reports of cognitive, functional, behavioral and/or emotional changes as first line evidence towards developing an index of suspicion for cognitive change; ○ make decisions regarding the appropriate selection of, and approach to, using a standardized, validated assessment tool for clinical assessment practices, depending on the cognitive profile that is presented (delirium, depression, dementia). ○ recognize the importance of referring clients to their physician for further evaluation when there is clinical evidence of early cognitive changes. ○ understand the importance of monitoring reported changes or difficulties over time to assess trends. Interdisciplinary professionals are advised to utilize regular annual or semi-regular client re- 	<p>Guidelines^(13,14, 15) Q^(16,17)</p> <p>Guidelines^(13,14,15,18)</p>	<p>B</p> <p>A</p>

** Strength of Recommendation

<p>evaluations as opportunities to assess for patterns of cognitive-related change over time (e.g., primary care nurses, community case managers, mental health counsellors).</p> <ul style="list-style-type: none"> • Given the seriousness of the burden of dementia for clients and caregivers, it is important for interdisciplinary health professionals to assist family physicians in early recognition and detection efforts by maintaining a high index of suspicion for cognitive-related changes such as: <ul style="list-style-type: none"> ○ reported or observed <u>functional decline</u> in <i>complex</i> ADL (change in ADL abilities in the early phase are often associated with <i>apathy</i>, e.g., change in appearance and hygiene,); ○ reported or observed <u>functional decline</u> in IADL (change in IADL abilities in the early phase are often associated with <i>loss of executive function</i> (e.g., variable loss of complex to simple financial skills such as identifying and explaining parts of a bank statement, identifying tipping convention and calculating tips or making change); ○ reported or observed <u>cognitive changes</u> such as: <ul style="list-style-type: none"> ▪ memory loss (episodic (time-related), semantic (idea-meaning), or other); ▪ partial or complete loss of attention or self-awareness (e.g., may be aware of some memory loss but unaware of the impact this loss has on physical or social functioning,etc.); ▪ language (e.g., word-seeking, incorrect use of words, changes in spoken/written comprehension); ▪ visuo-spatial changes or losses (e.g., reports of haphazard driving, recent history of falls); ○ reported or observed <u>mood changes</u> (e.g., apathy, irritability, depression); ○ reported or observed <u>behavioural changes</u> (e.g., changes in sleep, weight, social patterns, gross vs fine motor changes. gait changes, etc.) • Recommendations regarding the selection, approach and use of assessment techniques and tools appropriate for assessing cognitive-related changes: <ul style="list-style-type: none"> ○ The use of tools such as MMSE and CDT^{††} (clock drawing tool) in general cognitive assessment remain the accepted standard to reliably detect global cognitive losses associated with early to mid-stage dementias. ○ If the results of an MMSE are within normal range, but other presenting clinical data is suggestive 	<p>Guideline^(18,15)</p> <p>2^(19,20,21,22,23,24,25)</p> <p>2^(21,24,25,26,27)</p> <p>2⁽²⁸⁾, Q⁽²⁹⁾</p> <p>2^(1,2), Q^(3,4,19)</p> <p>2⁽³⁰⁾</p> <p>2^(31,32)</p> <p>1^(33, 34,35), 2⁽³⁵⁾</p> <p>1⁽³³⁾, 2^(35,36,37,38,39)</p> <p>1⁽⁴⁰⁾, 2^(41,42,43)</p>	<p style="text-align: center;">A</p> <p style="text-align: center;">A</p>
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^{††} **Note:** There are several methodologies in scoring the CDT. Recent evidence indicates that scoring methods may need to be selected in terms of the type of dementia which the CDT is screening for. Further investigation is required. At this time, CDT with any of the recognized scoring protocols is still recommended as a suitable screen for executive function and global cognitive impairment.

^{‡‡} **Important!** Interdisciplinary staff who choose to access any of the listed alternate tools are urged to fully read the accompanying instructions.

^{§§} Both the 15-item and 5 item tests has been found to be sensitive and reliable in detecting depression among healthy and medically ill older adults, but does the GDS does **not** retain its validity with individuals who have a mild to moderate dementia.

^{¶¶} Head-to-head studies of 4 different tools indicated that the Cornell Scale was one of the most consistent tools for detecting depression in AD, independently of the severity of dementia (Muller-Thomson et al, 2005).

<p>of cognitive loss, it is appropriate to consider the use of selected alternate tools to assist in further multi-domain assessment.</p> <ul style="list-style-type: none"> ○ The purpose for using additional multi-domain screens or tests is to supplement routine clinical assessment to confirm a suspicion of cognitive loss based on other presenting (often subtle) clinical evidence (e.g., positive history of risk factors, client or informant report, observed deficit). Upon confirmation of suspicion it is essential that a referral be made to the physician for diagnostic evaluation. ○ Cognitive-related changes as outlined above may have multiple etiologies, some of which are reversible. Changes should be presumed reversible until ruled-out otherwise. ○ Examples of additional or alternate assessment tools^{††} may include (but are not limited to): <ol style="list-style-type: none"> 1. <u>Montreal Cognitive Assessment (MoCA)</u> The MoCA is a standardized, validated screening tool for mild cognitive impairment, which can be used when the MMSE is high (e.g., 27 or >), but there is clinical evidence of cognitive impairment. The Montreal Cognitive Assessment (MoCA) is fully available for clinical use and available in the public domain at: http://www.mocatest.org/. 2. <u>Confusion Assessment Method (CAM)</u> This 2-part tool can be used for rapid evaluation of overall cognitive impairment and distinguishing the key features of delirium or reversible confusion from other cognitive impairments. It is available in the public domain at: http://www.hartfordign.org/publications/trythis/issue13.pdf 3. <u>Geriatric Depression Scale (GDS)</u> The original 30 item inventory has been modified twice, resulting in a 15-item and a 5-item inventory, both of which are sensitive and reliable in detecting depression among healthy, medically ill and very mildly cognitively impaired older adults^{§§}. These tools have been tested and used extensively in community, acute and long-term care settings. The 15 item version is available in the public domain in several languages at http://www.stanford.edu/~yesavage/GDS.html ; The shorter 5-item tool with scoring instructions is available in the public domain at: http://www.mrnc.org/mrnc_web/mrnc/nursinghome.aspx?ID=Downloads 4. <u>The Cornell Scale for Depression in Dementia</u> The Cornell Scale is the tool of choice^{***} for individuals with any significant impairment in cognition. This 19 item scale can be completed in a short interview (about 15-20 minutes) with a family member or caregiver. The Cornell Scale can be accessed at: http://www.emoryhealthcare.org/departments/fuqua/CornellScale.pdf 	<p>Guidelines^{13,15}</p> <p>1⁽⁴⁴⁾</p> <p>1⁽⁴⁵⁾</p> <p>2^(46,47,48)</p> <p>1⁽⁴⁹⁾</p>	<p>A</p> <p>A</p> <p>A</p> <p>A</p> <p>A</p>
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<p>5. <u>Psychogeriatric Assessment Scales (PAS)</u> The Psychogeriatric Assessment Scales (PAS) provide an assessment of the clinical changes seen in dementia and depression, and help to distinguish the two. The PASs strength is that it incorporates data from both the client and a reliable informant into one tool to give a more global perspective on client functioning. The tool is available in the public domain at http://www.mhri.edu.au/pas/</p> <p>6. <u>Beer's Criteria for Potentially Inappropriate Medication Use in the Elderly</u> This tool is one of the most widely used consensus based tools for appropriate medication use in the elderly. The original 1997 list of medications was last updated in 2003 – make sure you are using a current copy! A condensed Canadian version of Beer's Criteria is available from IHA's Pharmaceuticals and Therapeutics department. It is available on-line from the IH Intranet (no public access) at: http://insidenet.interiorhealth.ca/NR/rdonlyres/80AC7A3B-1557-4F5A-BD68-FC485CCCA033/20741/BeersCriteria2002.pdf However, a pdf document version is available here: Beer's Criteria revised list</p>	2 ^(50,51)	A
<p>2. <i>Recognition and assessment of Help-Seeking Behaviours, Patterns and Characteristics:</i></p> <ul style="list-style-type: none"> • Client and caregiver help-seeking behaviours and characteristics include: <ul style="list-style-type: none"> ○ subjective or caregiver complaints of changes in memory, behaviour, mood or function that are not previously documented or “taken seriously”; ○ confusion of meaning attributed to recognized changes; ○ history of help-seeking without satisfaction (“no answers” or no diagnosis); ○ confusion of health system contacts; ○ lack of a primary physician contact; ○ language or other factors (cultural, economic, etc.) that may be barriers to timely access; • Help-Seeking Pattern characteristics include: <ul style="list-style-type: none"> ○ Length of time since first symptom recognition; ○ Length of time since initial help-seeking; ○ Length of time from initial help-seeking to formal diagnosis; ○ Pathways that can be described as fragmented, crisis-initiated, dead-end, or smooth. 	Q ^(5,7,8,9,10)	B
<p>3. <i>Provide emotional support to client and caregiver through the uncertainty of the help-seeking process leading to diagnosis and disclosure.</i></p> <ul style="list-style-type: none"> • Provide neutral active listening and recognition of the client/caregiver experiences in help-seeking; • Assess client and caregiver coping and mood through the help-seeking process, including the frequency of day-to-day problems (rather than changes in cognitive measures) and the need for counselling, information and referral for interdisciplinary support services; • Support clients and caregivers in understanding the significance of observed changes in cognition, mood, behaviour and daily functioning and to seek physician consultation. • Be sensitive to various perspectives (client, caregiver, physician and societal and cultural views) 		

<p>concerning early diagnosis and disclosure of cognitive loss;</p> <ul style="list-style-type: none"> • Provide emotional support to clients and/or caregiver(s) during the uncertainty of the help-seeking ; For example, <ul style="list-style-type: none"> ○ Elicit the client and caregiver(s) beliefs and understanding about what is happening and what and how much information they wish to know. ○ Encourage open family discussion of questions, fears, observations; ○ Encourage clients and family members to write questions down <i>before</i> the doctor's appointment; ○ Encourage clients and family member(s) to discuss options to visit the physician together but provide opportunity for privacy if desired. ○ Use knowledge about the barriers and benefits associated with an early diagnosis and disclosure of cognitive loss to plan individualized care and support; 	<p>Q^(4,5,7,8,9,10,11,12) Systemic Review⁵² 3^(Group consensus)</p>	<p>C</p>
<p>4. Provide emotional support to client and family in the period immediately following diagnosis:</p> <ul style="list-style-type: none"> • Provide client and family support to first reactions (e.g., shock, anger, fear, embarrassment, relief, validation) in the first days and weeks following the receiving of a diagnosis of dementia; • Recognize the ethical dilemmas and challenges that arise when physician and caregiver beliefs, attitudes and practices about truth-telling of the diagnosis conflict with the individual client's rights (e.g., to know, to not know, for privacy of information, autonomous decision-making, etc.) and principles of practice (beneficence , non-maleficence "<i>do no harm</i>"). • Recognize that the decision to disclose the diagnosis of dementia is a complex one that needs to be considered individually. • Where available, provide access or refer the client and caregiver to post-diagnostic counselling^{†††} services to assist both clients and caregivers in the psychosocial adjustment and coping of dementia diagnoses and implications of the burden of disease. • Recognize client and caregiver needs for appropriate information and/or intervention and make the appropriate referral to Alzheimer Society^{†††} (http://www.alzheimer.ca/english/haveAD/intro.htm), Lewy Body Dementia Association (http://www.lewybodydementia.org/), the Association of Frontotemporal Dementias (http://www.ftd-picks.org/) or other relevant source of information.; 	<p>Q^(53,54,55,59) 3^(group consensus)</p> <p>Q^(56,57,58)</p> <p>Q^(53,55,57,58)</p> <p>Q^(59,60) & Systemic Reviews^(61,62)</p> <p>Guidelines^(13,15)</p>	<p>B</p> <p>B</p> <p>B</p> <p>B</p> <p>A</p>

^{†††} Additional anecdotal evidence was noted from participant comments during caregiver focus groups, conducted in Kelowna and Vernon in May and July 2006. Of the total 15 participants in two groups, there were two reports that post-diagnostic counselling had been received and was described as "extremely helpful" to adjust to the shock of diagnosis and to cope with early symptoms of depression. Several participants commented that post-diagnostic counselling had neither been mentioned or offered, and stated that such an option for care would have been appreciated and accessed in the weeks following disclosure of dementia if it had been offered to them.

^{†††} Note that the Alzheimer Society of Canada and its affiliates (ASBC) provides information, education and resources for all types of dementias, not just Alzheimer disease.

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