

Planning for the Future: The Road Ahead
Clinical Practice Recommendations to Support Clients and Caregivers

Introduction:

Facing an incurable and progressive disease such as dementia in oneself or a loved one is emotionally difficult. Clients and caregivers who have been given the diagnosis of disease may initially be in stages of shock or denial, but as the information settles, it will be time to start planning for the future. There are many things to plan for: financial, legal, health and personal (domestic) planning are key areas that will need attention. Clients need information to understand that they need to plan for a time when they will not be able to take care of personal affairs themselves. Caregivers need to prepare for the time ahead when hard choices will need to be made and surrogate decision-making will be needed. It is vital that caregivers know what the wishes of the individual would be for a full range of treatment, care, living and end-of-life arrangements as the course of dementia is often many years in duration.

At the current time, the most common practice is to approach families with selected* advanced planning requests for end-of-life or health care and treatments preferences at the point of transitional and often crisis care, e.g., upon admission to nursing homes^{1,2,3}, or an acute illness and admission to hospital⁴. While inquiring and eliciting information about treatment and end-of-life choices is necessary in such situations, it should be noted that these are not the optimal times to *initiate* advance planning. By this time, the person with dementia is frequently no longer capable of providing consent and direction, and families are called upon to be temporary substitute decision-makers. When there has been no prior discussion with the individual with dementia, decisions are made “in the best interest”, but this is not the same as fulfilling an individual’s stated directions or preference. A concerted effort to work “upstream” and initiate advance planning much earlier is required.

Interdisciplinary health providers can work with the client and family towards identifying the individual’s preferences and encourage advanced planning as early as possible in the course of dementia. Research shows that the majority of elderly people are willing to participate in end-of-life discussions when presented with an opportunity to do so^{5,6}. Research also demonstrates that individuals with early dementia desire to have knowledge of their diagnosis so they can “settle their affairs”^{7,8,9,10}. Finally, there is a small, but growing body of neuropsychiatric research that confirms decision-making capability which is present in early dementia is often lost by middle stage dementia, and highlights the early phase is a transient window of opportunity for decision-making that needs to be individually assessed and better utilized^{11,12,18}. When the person with dementia is provided with opportunities to participate to the full extent of their abilities in matters that require thought, discussion and ultimately choices and decisions which best represent their preferences, then their autonomy, right to self-determine, and dignity will more likely be upheld as decisional capacity is lost in advancing dementia.

* Note that this type of “advance planning” is selective and not comprehensive to meet all legal, financial, health care, personal and domestic needs.
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v.3, 14 July/2006, EA.

What are the issues?

The reported prevalence of advance directives in the general, community dwelling population of adults varies from 10-30%^{13,14}. Barriers to participating in advance planning of any nature include waiting for the physician[†] to bring up the topic¹⁵, reluctance to discuss illness, incapacity or death with family members, lack of time or procrastination, and most commonly, a lack of information, education, resources and support to complete the documentation^{16,17}. Providing an opportunity for participation and facilitating knowledge and discussion is key consideration for care. The role of interdisciplinary health providers is to provide the information, support and tools needed to assist individuals with early dementia to self-determine and express their choices, as well as their family caregivers.

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.

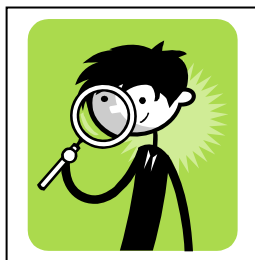
[†] In a recent study (Cavalieri et al, 2002) which surveyed family physicians about their practices of advising clients with mild to moderate Alzheimers disease and their families to plan ahead, 81% of physicians counselled some aspect of advance planning at some point in the disease, however 19% do not. Significantly, only 23% of physicians (63/271) responded to this survey. The authors concluded that physicians need to be more knowledgeable and proactive in their approaches to advance care planning for patients with mild to moderate Alzheimer's Disease.

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.



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.

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[§] 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 **assessment, referral and counselling support of advanced planning needs for persons with dementia and their caregivers.**

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 early dementia, as well as provide care to their family and or caregiver(s).</i>	Level of Evidence (sources cited)	SOR**
<ul style="list-style-type: none"> • Interdisciplinary health providers should have the following principle-based knowledge regarding decision-making capability and dementia: <ol style="list-style-type: none"> 1. In B.C., <u>all adults are presumed capable of autonomous decision-making until proven otherwise</u>. The diagnosis of dementia should not be considered analogous to a lack of decisional capability, particularly in the early stages of disease. The focus should be on how well the adult functions, and this requires providers to make a careful assessment of functional abilities. For example, when assessing financial abilities, inquire as to the person’s knowledge of income, expenses, banking institution, who pays bills, etc. It is important to remember that adults who are capable may accept or refuse support as they see fit, regardless of family will or insistence otherwise. 2. Adults <u>who need assistance should be treated in the most effective and least intrusive manner possible</u>. Mental capability is not black or white (present or not present) for all situations. Rather, it is a continuum 	<p>1^{11,12,18}</p> <p>1^{11,12,18}</p>	<p>B</p> <p>B</p>

** Strength of Recommendation

†† Note that a Representation Agreement is a legal plan that says who you give authority to if you need assistance managing your affairs. A Representation Agreement can cover financial and legal matters AND health and personal care matters. A Representation Agreement ends when you die; then your Will takes over.

‡‡ The media has highlighted the notion of “living wills”, and the public has quickly grasped the concept of legally stating their preferences. In BC, there is no “Living Will” Act or legislation, but it conceptually fits into the Representation Agreement. See resources at module end for a printout to answer this frequent client question.

§§ Only an individual capable adult (over the age of 19 in B.C.) can create advanced planning tools for themselves – family members or caregivers cannot make one for them. Adults have the right to make or *not to make* use of planning tools such as power of attorney or representation agreements.

*** Individuals with early dementia are able to describe their personal response to the disease, including how the disease has affected their perceptions of self (Burgener et al, 1999).

††† Note that the family physician may have already brought the topic up, but do not assume this. Where the topic has been previously introduced, and because advance planning is a process, this is an excellent opportunity to reinforce the message, provide support, answer questions, and refer the family to any needed resources.

‡‡‡ Sometimes it is easier to start the discussion in the financial/legal domain as it may be less personal and threatening than the health care/domestic domain;

§§§ In this situation, the Ulysses clause refers to the client giving consent to treatment or facility placement while capable of doing so, and providing additional powers to their substitute decision-maker to carry these wishes out, even if they later object and refuse these choices in an advanced stage of dementia.

**** See Advance Planning resource and information sheets listed at the end of this module, available for client teaching purposes.

<p>of diverse decisional abilities that reflects understanding, appreciation, reasoning and expression of choice. A loss in one aspect of decision-making does not necessarily mean a loss in another domain. For example, one may not be capable of independently managing one’s finances due to a loss of reasoning, but still be capable of deciding where to live, or who they will accept as caregiver because they can understand the risks and consequences or can express a preferred choice. Therefore, decisional capability needs to be assessed separately for each individual situation, and interventions need to be tailored to provide “just enough” help, and no more (least intrusive).</p>		
<ul style="list-style-type: none"> • Interdisciplinary health providers should have the following basic knowledge regarding advanced planning: <ul style="list-style-type: none"> ○ The biggest barrier to not planning for the future is the lack of information, resources and appropriate support to engage in family discussion. ○ Different laws provide different powers to provide consent when an individual cannot represent themselves. Health providers should have a basic awareness of both emergency/urgent and non-emergency/not urgent decision-making authority when the individual is not capable. ○ Health providers should have a basic understanding of the tools and laws in BC when someone needs assistance with decision-making and managing their affairs. Specifically, health providers should be knowledgeable about: <ul style="list-style-type: none"> • power of attorney (standard bank vs. enduring clause) • representation agreement^{††} (standard power (Section 7) vs. additional power (Section 9)); • “living wills^{††}” • know where to refer people to for further information and resources; 	<p>2^(13,14,15,16)</p> <p>3¹⁹: See resources</p> <p>3: See resources</p>	<p>B</p> <p>C</p> <p>C</p>
<ul style="list-style-type: none"> • The advanced planning 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; ○ address the client directly^{§§} and let them speak for themselves whenever and wherever possible (respectful caring), including when interviewed together with caregiver^{***}. ○ 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 assess emotional readiness to discuss advanced planning needs; ○ inquire as to whether they have thought about the short and long-term future^{†††} and if any any steps have been taken to prepare and plan; (“Have you thought about...?”). ○ acknowledge the emotional difficulty in addressing future needs while at the same time highlighting the importance and benefits of advanced planning when faced with a progressive debilitating condition such 	<p>Q²⁰</p>	<p>B</p>

<p>as dementia. Some important points for discussion include:</p> <ul style="list-style-type: none"> • the diagnosis of dementia means the eventual loss of insight, judgement, reasoning and memory needed to self-determine and make decisions. • the eventual need for family or caregiver to be a substitute decision-maker in matters of finance, legal, health care situations and for personal care arrangements; • the critical importance of accurately representing the individual’s preferences when they are no longer able to do so themselves; • the knowledge and discussion of individual wishes ahead of time relieves some of the decision-making burden on the family, especially if crisis situations occur in future; • what would happen if financial or legal matters are not attended to; • the role of health providers in counselling and supporting individuals to advance plan if so desired. <ul style="list-style-type: none"> ○ provide a framework for discussion regarding advanced planning needs. A suggested approach is to divide the topic of advanced planning into two areas: <ul style="list-style-type: none"> • legal and financial arrangements^{†††}, and; • health care and personal/domestic arrangements; ○ Within this divided framework, a simple 4-step approach includes: <ol style="list-style-type: none"> 1) “Think about”: Find the resources and information needed to get informed and understand the issues; 2) “Discuss”: Inform, involve and discuss the issues with loved ones, family, caregivers as needed; 3) “Notify”: When decisions are made, consider ensuring that all relevant family members are aware; Notifying ones physician of health care decisions is also advisable. 4) “Write Down”: Leave preferences clearly written down. The best means for this is in a legal plan, such as a standard representation agreement, but any means of writing preferences down, dating it, and keeping it in a safe place identified to family, is advisable. <ul style="list-style-type: none"> • Assess client and caregiver knowledge regarding legal and financial arrangements and inquire if they need: <ul style="list-style-type: none"> ○ information to assist in the “think about” stage of financial and legal arrangements. For example, do they need information on: <ul style="list-style-type: none"> • the types of financial and legal decisions that may/will need to be made in the future: <ul style="list-style-type: none"> ➢ everyday banking and investment management; ➢ clarifying access to money, cheques, etc. when capacity is lost; ➢ real estate management (e.g., selling of a property if needed); ➢ selling a vehicle or other large property items (trailers, boats, etc.) ➢ wills, tax and estate planning (e.g., accessing tax information, applying for tax credits) 	<p>3: See resources</p> <p>3</p> <p>3: See resources</p>	<p>C</p> <p>C</p> <p>C</p>
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<ul style="list-style-type: none"> • the types of financial and legal options available in B.C. to manage their affairs: <ul style="list-style-type: none"> ➢ power of attorney (clarify standard vs enduring clause) ➢ representation agreement (clarify standard power vs. additional power); ○ planning tools to assist in the “think about” stage of financial and legal arrangements <ul style="list-style-type: none"> • Assess client and caregiver knowledge regarding the health care and personal/domestic arrangements, and inquire if they need: <ul style="list-style-type: none"> ○ information to assist in the “think about” stage of health care and personal/domestic arrangements. For example do they need information on: <ul style="list-style-type: none"> • types of health care decisions that may need to be made in future: surgery, dental work, immunizations, medications; • types of domestic decisions that will need to be made in future: changing domestic roles within the home and the division of labour (e.g., mowing the lawn, cooking, bill paying, driving, furnace maintenance, and other care needs of the home and yard, etc.) • types of personal care preferences regarding home support, making living arrangements, spiritual arrangements; • broader personal and health care decisions such as levels of life support or intervention, physical restraints, Ulysses clause^{§§§}; ○ planning tools to assist in the “think about” stage of health care/personal/domestic planning arrangements. 	<p>3: See Resources</p>	<p>C</p>
<ul style="list-style-type: none"> • Provide appropriate and timely information^{****} to address client and caregiver concerns and learning needs. Research indicates that giving small frequent sources of information is better than providing a large amount of information at once. The type and amount of information needs to be uniquely tailored for individual client and caregiver specific needs, and asking the client and caregiver as to what they perceive their priorities to be is the right place to start. 	<p>Q^{21, 22}</p>	<p>B</p>
<ul style="list-style-type: none"> • Remind the client and caregiver that advance planning is a process and will take some time to complete. Health providers should continue to follow-up over time to provide encouragement, support and answer questions. 	<p>3</p>	<p>C</p>

Resources for Advanced Planning

There are several client and caregiver educational resources available. It is important to remember to select appropriate information and resources which reflect current and accurate information, and which are intended for populations within the jurisdiction of British Columbia.

Client and Caregiver Information and Planning Tools:

1. Useful Web-links:

a. General Information on Planning:

- Alzheimer Society of Canada: [“Planning for the Future”](#);
- Public Guardian and Trustee of B.C.: [“Plan Now to Protect Your Future”](#)

b. Information on Financial and Legal Planning:

- Canadian Bar Association, British Columbia: [“Power of Attorney and Representation Agreements”](#) (general question and answers)
- Representation Agreement Resource Center (BC):
 - [“What is a Power of Attorney?”](#)
 - [“When I need Help with Decision-Making”](#) (Representation Agreements)
 - [“Make and Register a Representation Agreement”](#) (How-to guide)
 - [“How does a “Living Will” Fit In?”](#)
 - [Just Sign Here](#)
 - [“Do you have a Will?”](#) and [“Making a will”](#)
 - [“Registering a will”](#) (note: registration of a will is completely optional)
- Public Guardian and Trustee of B.C.:
 - [“How you Can Help People Manage Finances and Legal Matters When They Cannot Manage On their Own”](#)
 - [“Its Your Choice: A Guide to Making a Representation Agreement”](#)

c. Information on Health Care Planning:

- [What Adults, Families and Health Care Providers Need to Know About Consent to Health Care](#). (PGT)
- [Health Care Decisions : Your Rights and the Law](#) (January 2005) (plain language information on the Health Care Consent Act)

d. Information on Government Services and Financial Benefit Programs:

- Government of Canada, Human Resources and Social Development. [“Guide to Canada Pension Plan Disability Benefits”](#) (for financial planning and application when individual is under 65 years of age with early onset dementia)
- Government of Canada, Human Resources and Social Development. [“Consent to Communicate Information to a Representative”](#) (needed to communicate and represent the individual with dementia to the federal government)

Phased Dementia Pathway – Early Dementia Phase

- Canada Benefits Finder Guide. “[I am a senior living in British Columbia](#)”.
- Canada Benefits Finder Guide. “[I am a person with a disability living in British Columbia](#)”
- Veterans Affairs Canada. “[A Guide to Access VAC Health Benefits and the Veterans Independence Program](#)”
- Veterans Affairs Canada. “[Benefits for Primary Caregivers](#)”
- Veterans Affairs Canada “[Alzheimer Wandering Registry Program for Veterans](#)” (see Alzheimer Society of Canada for wandering program registry for non-veterans)

Health Professional Information:

(Note: the sites below are intended for professional education and supporting clinical decision-making, while the materials listed above are more suitable for printing out for client teaching purposes)

Questions regarding decision-making and capability:

- “[Who is considered legally capable to make Representation Agreements?](#)”
- “[Who has legal authority to make decisions for BC adults 19 years or older?](#)” (reference chart)
- “[Who can make health care decisions if an adult is incapable of giving consent as determined by the health service provider who is proposing the health care?](#)” November 2003, RARC. (reference chart)
- “[Tools and Laws When Someone Needs Assistance with Decision-Making and Managing Their Affairs](#)” (reference chart)

Questions regarding Health Care consent:

- [What Adults, Families and Health Care Providers Need to Know About Consent to Health Care.](#) (PGT)

Legal Tools:

- “[What is a Power of Attorney?](#)”
- “[What is a Representation Agreement?](#)”
- [Definition of Routine Management of Financial Affairs](#)^{tttt}
- [Power of Attorney or Representation Agreement?](#) Information for Professionals.
- [Adult Guardianship](#)
- [Trustee of Pension](#) (application form)
- [Committeeship](#)
 - [When to Use](#)
 - [Fact Sheet for Private Committees](#)

^{tttt} defined as per the *Representation Agreement Act* regulations, September 2001.

General Resources:

- Veterans Affairs Canada – [“Providers and Professionals”](#)

Toolkit for problem-solving existing financial and legal challenges and dementia:

By far and away, a preventative approach to advance planning is preferable to problem-solving financial, legal and personal crises down the road. That said, family practice physicians and interdisciplinary staff in all settings frequently find themselves trying to assist, counsel and clinically problem-solve client situations that are legal and ethical quagmires of uncertainty. The following toolkit provides some basic resources to understanding and using the laws in BC to protect clients and their property.

- [“Tools and Laws When Someone Needs Assistance with Decision-Making and Managing Their Affairs”](#) (reference chart)
- [Contact Information for the Public Guardian and Trustee of BC](#)
- [Practice Guidelines for Certificate of Incapability Assessments under the *Patients Property Act*](#) (March 2005) (for physicians, mental health teams, social workers, etc.)

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