



CANADIAN CENTRE FOR
ELDER LAW

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First published on November 9, 2016.

Revised November 16, 2017

Health Care Consent, Aging and Dementia: Mapping Law and Practice in British Columbia

BACKGROUNDER

Introduction

The Canadian Centre for Elder Law (“CCEL”), in collaboration with the Alzheimer Society of British Columbia (“The Society”), has embarked on a project that examines the law, policy and practice of consent to health care in the context of aging and dementia. This 16-month project funded by the Law Foundation of British Columbia will involve extensive comparative legal research on informed consent and interrelated areas of the law, as well as stakeholder consultation. The work will be informed by an expert interdisciplinary advisory committee (see page 7 for the members). Research will culminate in a report identifying areas for law, policy and practice reform, and at least one plain language educational resource on health care consent rights.

Objectives of the Project

This project aims to:

- Document the experiences of people living with dementia, family caregivers, substitute decision-makers, and health care providers with respect to use of medication and consent in BC;
- Summarize the law in BC with respect to health care consent;
- Map knowledge, policy issues, and legal concerns related to the use of anti-psychotics and anti-depressants for people living with dementia;
- Bridge a wide variety of social policy research with implications for legal practice;
- Identify differing and innovative approaches taken in other jurisdictions in Canada as well as the United Kingdom, the United States and Australia vis-à-vis law and policy around health care consent, particularly with respect to older adults and people living with dementia;
- Suggest potential areas for law, policy and practice reform in BC, including education and professional development;
- Raise further awareness on the right to informed health care consent among British Columbians;
- Produce a foundation of research that will support the key people engaged in this issue to appreciate the topic from a perspective that respects the rights of older adults, people living with dementia and substitute decision-makers; and

- Publish at least one public legal education resource to assist people living with dementia, substitute decision-makers, and family caregivers to understand their rights and responsibilities with respect to health care consent.

Project Methodology:

The Project will involve the following activities:

- Establishing a diverse project advisory committee that will meet approximately six to eight times to guide the work of the CCEL and The Society as needed on this Project;
- Interviewing a range of experts and health care providers on the topic of medication, informed consent and older adults with dementia;
- Holding a series of focus groups providing people living with dementia, family caregivers, and substitute decision-makers with an opportunity to share their experiences in relation to informed consent, medication and treatment for adults living with dementia;
- Undertaking a comprehensive review of relevant legislation and jurisprudence in BC;
- Completing comparative research considering key jurisdictions in Canada and abroad, such as Ontario, the United Kingdom and Australia;
- Completing a literature review on the subject including social science academic material from journals and reports as well as publications from the legal community;
- Producing a report that makes recommendations for law reform, policy, and practice, including education and training for BC, following a summary of:
 - The views and concerns of key professional stakeholders on the subject of medication and older adults living with dementia;
 - Findings from our interviews with people living with dementia, substitute decision-makers, and family caregivers regarding medication and treatment of older adults living with dementia;
 - Relevant legislation; and
 - Legal models and legislative provisions from other jurisdictions of note;
- Reviewing existing public legal education resources on the right to informed consent to health care, and developing a straight-forward plain language resource for BC.

Rationale for the Project

Provincial and territorial data from Statistics Canada 2011 Census shows that BC has one of the largest growing populations of seniors in Canada. As our population continues to age, many British Columbians will be living with dementia, or caring for someone who is living with dementia. Although prevalence can

be difficult to estimate, due to the challenges of getting a diagnosis, research suggests that between 60,000 and 70,000 British Columbians have been diagnosed with some form of dementia.¹

In recent years, a number of studies have raised concerns regarding potential over-medication and inappropriate medication prescribing for older adults. In 2015, the BC Seniors Advocate noted that it is estimated that up to 51% of residents in BC care facilities are taking nine or more different medications.² A 2011 Ministry of Health report revealed both significant use of anti-psychotics, and concerns regarding lack of appropriate consent to treatment and engagement of family in developing care plans.³

More recently, the BC Seniors Advocate has identified extensive use of both anti-psychotics and antidepressants in residential care as an area of particular concern, reporting that 34% of seniors in residential care are prescribed anti-psychotic medications.⁴ The Ministry of Health has stated that use of anti-psychotics in residential care is primarily in response to the increasing number of residents with dementia presenting with associated behavioural symptoms.⁵

Over-medication and inappropriate medication is an issue of particular concern with respect to older adults because they may be at an increased risk of adverse effects due to the way that older adults' bodies process medications.⁶ Side effects of medications range from unpleasant to debilitating. Anti-psychotics are no exception, and need to be prescribed with careful consideration; non-pharmacological management needs to be explored first (where safe to do so), and less toxic medications need to be considered whenever possible.⁷ Anti-psychotics can inadvertently cause Parkinson's-like side effects which can be mistaken for Parkinson's Disease at times, resulting in more incorrectly prescribing.

Various resources have been developed to support enhanced practice with respect to the administration of medication. In particular, the BC Ministry of Health published *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care* in 2012.⁸ The BC Care Providers Association also published a *Best Practices Guide for Reducing Anti-Psychotic Drug Use in Residential Care* in 2013.⁹ In response to concerns related to anti-psychotic prescribing, the BC Patient Safety and Quality Council has created the CLeAR (Call for Less Antipsychotics in Residential Care) Initiative, which has focused on both improving non-pharmacological approaches to dementia-related behaviours and thoughtful prescribing of medications for medication-responsive symptoms. For

¹ Medical Service Economic Analysis, Health System Planning Division, Ministry of Health, Dementia (age 45+ years only) January 17, 2011, project 2010_372. Centre for Applied Research in Mental Health and Addictions, Simon Fraser University, 2006.

² Office of the Seniors Advocate, "Placement, Drugs and Therapy: We Can Do Better", Report #3, April 2015, at 7, online: <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2015/09/PlacementReport.pdf> ("Placement, Drugs and Therapy").

³ British Columbia Ministry of Health, "A Review of the Use of Anti-psychotic Drugs in BC Residential Care", December 2011, online: <http://www.health.gov.bc.ca/library/publications/year/2011/use-of-antipsychotic-drugs.pdf> ("A Review of the Use of Anti-psychotic Drugs")

⁴ Placement, Drugs and Therapy, *supra* note 2 at 8.

⁵ British Columbia, Ministry of Health, *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care: A Person-Centered Interdisciplinary Approach* (2012), online: <http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf> [BC Ministry of Health].

⁶ A Review of the Use of Anti-psychotic Drugs, *supra* note 3 at 7.

⁷ BC Ministry of Health, *supra* note 5 at 9.

⁸ *Ibid.*

⁹ BC Care Providers Association, *Best Practices Guide for Reducing Anti-Psychotic Drug Use in Residential Care: Ensuring Residential Care Homes are Safe Places to Live and Work* (2013), online: <http://www.bccare.ca/wp-content/uploads/Anti-Psychotics-Guide-hr-06-05-13.pdf>.

those facilities who have participated in this voluntary initiative, significant reductions in prescribing of anti-psychotics has occurred.¹⁰

One of the key aspects of appropriate prescribing of anti-psychotics and other medications is the issue of informed consent. There remains a need to develop a rights-based understanding of health care consent to complement the dominant health care orientation. Limited research addresses consent issues in relation to medication, which can raise particular challenges in the context of diseases such as Alzheimer's and related dementias, which can compromise cognition and capacity, or be associated with myths and assumptions regarding incapacity. There is also a need to develop resources to assist substitute decision-makers, health care providers, older adults, and family caregivers to better understand the scope of the right to informed consent. Understanding of potential side effects and drug interactions is important given the number of medications seniors may be using at once.¹¹

The right to consent to medication and treatment is a fundamental right enshrined in BC law. Decisions regarding medication have a significant impact on quality of life and life expectancy, and older people and substitute decision-makers often do not appreciate the right to ask questions, explore alternatives, and provide consent. Older people living with dementia are a vulnerable, growing subset of BC's population; however, ultimately the issue of consent to health treatment matters to everyone, and this project's research will support a robust understanding of the right to informed consent in BC that will benefit anyone receiving treatment, or consenting to treatment on behalf of another person. In particular, project findings will be of benefit to people living with disabilities other than dementia, as people in other communities, such as the community living sector, suffer from exclusion from health care decision-making due to assumptions around mental capacity, and lack of respect for the right to informed consent.

Legal Background

The practice of health care consent in the context of dementia raises legal issues related to health law, substitute decision-making legislation, workplace safety, and human rights. While recent research has shined a spotlight on the use of anti-psychotics in residential care, the right to consent to medication applies to all medication and treatment, in community, hospital, and long term care settings—although different laws and regulations may apply depending on the context of care.

Health Care Consent Law

In BC, the law of health care consent for adults is governed primarily by the *Health Care (Consent) and Care Facility (Admission) Act* ("HCCA").¹² Pursuant to this Act, every adult is presumed capable of giving, refusing and revoking consent to health care,¹³ and a health care provider cannot provide health care without first obtaining the adult's consent.¹⁴ Health care is defined as "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health...".¹⁵ The legislation

¹⁰ BC Patient Safety and Quality Council and Reichert and Associates, Clear Wave 2 Final Evaluation Report, online: < https://bcpsqc.ca/documents/2015/01/2017-CLear-Wave-2-Evaluation-Report-Aug-3-2017_FINAL.pdf >.

¹¹ Reason, B., Turner, M., McKeag, A. M., Tipper, B., & Webster, G. (2012). The impact of polypharmacy on the health of Canadian seniors. *Family practice*, 29(4), 427-432.

¹² RSBC 1996, c 181 ("HCCA").

¹³ HCCA, s 3. See also *Representation Agreement Act*, s 3.

¹⁴ HCCA, s 5.

¹⁵ HCCA, s 1.

sets out the elements and scope of consent,¹⁶ and the three limited exceptions to the requirement to obtain the consent of the adult: incapacity;¹⁷ emergency;¹⁸ and preliminary examination.¹⁹ Importantly, the legislation also sets out in descending order of hierarchy who may act as a temporary substitute decision-maker in cases of incapacity. The Act is said to be a codification of the common-law doctrine of “informed consent”.

The *Residential Care Regulation* deals with consent in the context of the using medication as a form of chemical restraint within the long term care environment.²⁰ Only a few Canadian provinces have enacted health care consent legislation, the remainder preferring to rely on the common law doctrine.²¹

A full examination of health care consent laws in BC requires a review, not only of the common-law doctrine of informed consent and statutory consent laws, but also of the broader legal framework. This project endeavours to contextualize consent laws within this broader legal framework by also considering the following interrelated areas of law.

Capacity and Substitute Decision-Making

Where adults are found incapable, health care providers must obtain consent for health care decisions from their substitute decision-makers, and make decisions in accordance with any advance directive. Advance directives provide legally binding instructions to health care providers regarding which health care a person consents to in the future should they become incapable. Advance directives are governed by the HCCA.

Substitute decision-makers may be:

- Representatives under the *Representation Agreements Act*
- Temporary substitute decision-makers under the HCCA
- Committees of the person under the *Patients Property Act*

Mental Health and Involuntary Committal Laws

In BC, a person in need of psychiatric care can be involuntarily committed to a designated psychiatric facility, and treated without their consent: pursuant to s. 31(1) of the *Mental Health Act*, treatment of an involuntary patient which is authorized by the director of the facility is “deemed to be given with the consent of the patient”.²² This provision effectively enables adults with dementia to be admitted to residential care facilities and prescribed anti-psychotic medications without the consent of the adult or their substitute decision-maker. This “deemed consent” provision is at odds with legislation in other prov-

¹⁶ HCCA, ss 6-9.

¹⁷ If patient found incapable, may obtain consent from the substitute decision maker: s 11 (personal guardian or representative) and s 16 (TSDM) HCCA.

¹⁸ Urgent or emergency health care: “in order to preserve the adult's life, to prevent serious physical or mental harm or to alleviate severe pain”, s 12 HCCA.

¹⁹ To “undertake triage or another kind of preliminary examination, treatment or diagnosis”, s. 13 HCCA.

²⁰ *Residential Care Regulation*, ss 73-75.

²¹ Ontario, British Columbia, New Brunswick, Prince Edward Island and Yukon have health care consent statutes.

²² *Mental Health Act*, RSBC 1996, c 288, s 31(1).

inces, such as Ontario, whereby consent must be given by the adult, or by the adult's substitute decision-maker.²³ The "deemed consent" and related provisions are currently subject to a Charter challenge in the Supreme Court of BC.²⁴

Health Care Regulation and Professional Responsibility

In addition to provincial health care consent laws, regulated health care professions are required to comply with their governing bodies' codes and standards, and are guided by internal guidelines produced by them. Some such governing bodies have standards and/or guidelines specifically addressing consent to health care, such as the College of Registered Nurses of British Columbia. Others, such as the College of Physicians and Surgeons of BC, do not.

International and Domestic Human Rights and Discrimination Law

Canada is a signatory to the *International Convention on the Rights of Persons with Disabilities*, which broadly speaking promotes individual autonomy, the freedom to make one's own choices, full participation, equality and non-discrimination, and in particular, under article 12, enshrines the right of people with disabilities to participate in decisions about their own lives.²⁵ Further, BC human rights law prohibits discrimination on the basis of age, disability and gender, amongst other grounds.²⁶ In the context of a vulnerable population of older adults living with dementia, the interplay of disability, discrimination law and health care law is evident. Consequently, applying a human rights lens to a review of health care consent law as it affects older adults may provide an important perspective on this issue, and help illuminate areas where people living with dementia are treated differently from people living with other forms of disability, or other health conditions.

Workplace Safety Laws and Staffing Regulations

Employers have a statutory obligation under occupational health and safety laws to ensure the safety of all employees.²⁷ Employers have an obligation to undertake a violence risk assessment,²⁸ and are responsible for educating and training workers in violence prevention strategies, and informing workers of what they need to do if a resident becomes violent.²⁹ In addition, the *Residential Care Regulation* sets minimum standards for staffing coverage and training—which must be appropriate to meet the needs of persons in care—as well as requires designated programming for the physical, social and recreational activities for persons in care.³⁰ The relationship between staff safety, staffing coverage, and training is highly relevant in the context of evidence which suggests that best practice for treatment of behavioural

²³ *Health Care Consent Act*, SO 1996, c 2; See also Verdun-Jones, S. & Lawrence, M. "The Charter Right to Refuse Psychiatric Treatment: A Comparative Analysis of the Laws of Ontario and British Columbia Concerning the Right of Mental-Health Patients to Refuse Psychiatric Treatment" (2013) 46 UBC L Rev 489 – 527.

²⁴ Mary Louise MacLaren, D.C. & Council of Canadians with Disabilities v. Attorney General of BC, Supreme Court of British Columbia; See also <http://www.clasbc.net/charter_challenge_forced_psychiatric_treatment>

²⁵ *Convention on the Rights of Persons with Disabilities*, Arts. 3 and 12.

²⁶ *Human Rights Code*, RSBC 1996, c 210.

²⁷ *Workers Compensation Act*, RSBC 1996, c 492, s 115

²⁸ Occupational Health and Safety Regulation, BC Reg. 296/97, s 4.27 - 4.31.

²⁹ WorkSafe BC, "Dementia: Understanding Risks and Preventing Violence", online: <<https://www.worksafebc.com/en/resources/health-safety/books-guides/dementia-understanding-risks-and-preventing-violence?lang=en>>

³⁰ *Residential Care Regulation*, ss 45 & 55.

symptoms of dementia is “comprehensive, individualized assessment in order to provide person-centred care, with family and professional caregiver education and support”.³¹

Project Committee Members

As with many CCEL projects, an advisory committee will provide ongoing project guidance regarding research and consultation methodology, key stakeholders and recommendations to flow from research. The advisory committee members are:

Dr. Heather D’Oyley, Geriatric Psychiatrist and Physician Lead, Vancouver Coastal Community Older Adult Mental Health and Substance Use

Dr. Elisabeth Drance, Family member (caregiver) and Geriatric Psychiatrist, Vancouver Coastal Health and Providence Health Care

Tara Fitzgerald, Quality Leader, Seniors Care, BC Patient Safety & Quality Council

Isabel Grant, Professor, Peter Allard School of Law, University of British Columbia

Laura Johnston, Lawyer, Community Legal Assistance Society

Michael Kary, Director of Policy and Research, BC Care Providers Association

Alison Leaney, Provincial Coordinator, Vulnerable Adults Community Response, Public Guardian and Trustee

Martha Jane Lewis, Executive Director, Seniors First BC

Barbara Lindsay, Director, Advocacy & Education, Alzheimer Society of BC

Isobel Mackenzie, BC Seniors Advocate

Jim Mann, Person living with dementia

Dr. Deborah O’Connor, Professor, School of Social Work, and Co-director, Centre for Research on Personhood and Dementia, University of British Columbia

Lisa A. Peters, Partner, Lawson Lundell LLP and Chair, BC Law Institute

Michael Vonn, Policy Director, BC Civil Liberties Association

Penny A. Washington, Partner, Dispute Resolution & Litigation, Norton Rose Fulbright

31 Alzheimer’s Australia, “The Use of Restraints and Psychotropic Medications in People With Dementia”, Paper No 38, March 2014, at 8 online: < <https://www.fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-38.pdf>>.

About the CCEL

The CCEL carries out scholarly research, writing, analysis and community engagement relating to legal and policy issues that impact older adults. As part of its work the CCEL consults with stakeholders, collaborates with numerous community agencies, and publishes legal, policy and practice resources, including recommendations for law reform, and public information materials. The CCEL is a division of the British Columbia Law Institute, BC's non-profit independent law reform agency.

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