

# THE STATE OF KNOWLEDGE ON **ADVANCE REQUESTS** FOR **MEDICAL ASSISTANCE** IN **DYING**

The Expert Panel Working Group on  
Advance Requests for MAID



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FOR MEDICAL ASSISTANCE IN DYING**

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## THE COUNCIL OF CANADIAN ACADEMIES

180 Elgin Street, Suite 1401, Ottawa, ON, Canada K2P 2K3

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This report was prepared for the Government of Canada in response to a request from the Minister of Health and the Minister of Justice and Attorney General of Canada. Any opinions, findings, or conclusions expressed in this publication are those of the authors, the Expert Panel Working Group on Advance Requests for MAID, and do not necessarily represent the views of their organizations of affiliation or employment, or of the sponsoring organizations, Health Canada and the Department of Justice Canada.

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## The Expert Panel on Medical Assistance in Dying

Under the guidance of its Scientific Advisory Committee, Board of Directors, and the Academies, the CCA assembled the Expert Panel on Medical Assistance in Dying to undertake this project. Each expert was selected for their expertise, experience, and demonstrated leadership in fields relevant to this project.

**Hon. Marie Deschamps, C.C., Ad. E. (Chair of the Expert Panel)**, Former Justice of the Supreme Court of Canada and Adjunct Professor, McGill University (Montréal, QC) and Université de Sherbrooke (Sherbrooke, QC)

## The Expert Panel Working Group on MAID for Mature Minors

**Dawn Davies (Working Group Chair)**, Associate Professor, Department of Pediatrics, University of Ottawa; Palliative Care Physician, Roger Neilson House/Children's Hospital of Eastern Ontario (Ottawa, ON)

**Gail Beck, O.Ont.**, Clinical Director, Youth Psychiatry Program, The Royal (Ottawa, ON)

**Carrie Bourassa**, Chair, Northern and Indigenous Health, Health Science North Research Institute, and Scientific Director, Institute of Indigenous Peoples' Health – Canadian Institute of Health Research (Sudbury, ON)

**Franco A. Carnevale**, Professor, Ingram School of Nursing, McGill University (Montréal, QC)

**Joanna Chung**, Psychologist, Medical Psychology and Hematology/Oncology/Bone Marrow Transplant Program, BC Children's Hospital (Vancouver, BC)

**Joan Gilmour**, Professor, Osgoode Hall Law School, York University (Toronto, ON)

**Hon. Stephen Goudge, Q.C., O.Ont.**, Counsel, Paliare Roland (Toronto, ON)

**Mary Ellen Macdonald**, Associate Professor, Faculty of Dentistry, McGill University (Montréal, QC)

**Jean-Pierre Ménard, Ad. E.**, Lawyer, Ménard, Martin, Avocats (Montréal, QC)

**Cheryl Milne**, Executive Director, David Asper Centre for Constitutional Rights, Faculty of Law, University of Toronto (Toronto, ON)

**Ubaka Ogbogu**, Assistant Professor, Faculties of Law and Pharmacy & Pharmaceutical Sciences, University of Alberta (Edmonton, AB)

**Bryan Salte**, Associate Registrar and Legal Counsel, College of Physicians and Surgeons of Saskatchewan (Saskatoon, SK)

**Kimberley Widger**, Assistant Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto; Nursing Research Associate, Paediatric Advanced Care Team, Hospital for Sick Children (Toronto, ON)

**Randi Zlotnik Shaul**, Director, Department of Bioethics, The Hospital for Sick Children (Toronto, ON)

## The Expert Panel Working Group on Advance Requests for MAID

**Jennifer L. Gibson (Working Group Chair)**, Sun Life Financial Chair in Bioethics and Director, University of Toronto Joint Centre for Bioethics (Toronto, ON)

**Benjamin L. Berger**, Professor, Osgoode Hall Law School, York University (Toronto, ON)

**Martha Donnelly**, Geriatric Psychiatrist; Associate Professor Emeritus, Department of Psychiatry, University of British Columbia (Vancouver, BC)

**Alika Lafontaine**, Medical Director North Zone Indigenous Health, Alberta Health Services; Assistant Clinical Professor of Medicine, Anesthesiology and Pain Medicine, University of Alberta; Medical Director, Alignment by Design Labs (Grande Prairie, AB)

**Trudo Lemmens**, Professor and Scholl Chair in Health Law and Policy, Faculty of Law, University of Toronto (Toronto, ON)

**Susan MacDonald**, Associate Professor, Medicine & Family Medicine, Memorial University of Newfoundland (St. John's, NL)

**Sheila A.M. McLean**, Emeritus Professor, Law & Ethics in Medicine, Glasgow University (Glasgow, Scotland)

**Dorothy Pringle, O.C., FCAHS**, Professor Emeritus, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto (Toronto, ON)

**Patricia (Paddy) Rodney**, Associate Professor, School of Nursing and Faculty Associate, W. Maurice Young Centre for Applied Ethics, University of British Columbia (Vancouver, BC)

**Harvey Schipper**, Professor of Medicine and Adjunct Professor of Law, University of Toronto (Toronto, ON)

**Samir Sinha**, Peter and Shelagh Godsoe Chair in Geriatrics and Director of Geriatrics, Sinai Health System and University Health Network; Associate Professor of Medicine, Family & Community Medicine, and Health Policy, Management and Evaluation, University of Toronto (Toronto, ON)

**Tim Stainton**, Professor, School of Social Work, University of British Columbia (Vancouver, BC)

**Ross Upshur**, Professor, Department of Family & Community Medicine and Dalla Lana School of Public Health, University of Toronto; Associate Director, Lunenfeld Tanenbaum Research Institute; Scientific Director, Bridgepoint Collaboratory for Research and Innovation, Sinai Health System (Toronto, ON)

**Agnes van der Heide**, Professor and Researcher, Erasmus University Medical Center Rotterdam (Rotterdam, the Netherlands)

## The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition

**Kwame McKenzie (Working Group Chair)**, CEO, Wellesley Institute; Professor of Psychiatry, University of Toronto; Medical Director, Health Equity, Centre for Addiction and Mental Health; Commissioner, Ontario Human Rights Commission (Toronto, ON)

**Melissa K. Andrew**, Associate Professor, Medicine (Geriatrics), Dalhousie University and Nova Scotia Health Authority (Halifax, NS)

**Jennifer A. Chandler**, Bertram Loeb Research Chair, Full Professor, Centre for Health Law, Policy and Ethics, Faculty of Law, University of Ottawa (Ottawa, ON)

**Pierre Deschamps, C.M.**, Member of Research Group on Health and Law, McGill University (Montréal, QC)

**Jocelyn Downie, C.M., FRSC, FCAHS**, University Research Professor, Faculties of Law and Medicine, Dalhousie University (Halifax, NS)

**Martin Drapeau**, Professor, Counselling Psychology and Psychiatry, McGill University (Montréal, QC)

**Colleen M. Flood, FRSC, FCAHS**, Director, Centre for Health Law Policy and Ethics; Professor and Research Chair in Health Law and Policy, University of Ottawa (Ottawa, ON)

**Arthur W. Frank, FRSC**, Professor Emeritus, Department of Sociology, University of Calgary (retired) (Calgary, AB); Professor II, VID Specialized University (Oslo, Norway)

**K. Sonu Gaiind**, Chief of Psychiatry/Medical Director of Mental Health, Humber River Hospital; Associate Professor, University of Toronto; Board Member, World Psychiatric Association (Toronto, ON)

**Mona Gupta**, Associate Professor and Psychiatrist, Centre hospitalier de l'Université de Montréal (CHUM) (Montréal, QC)

**Scott Y.H. Kim**, Senior Investigator, Department of Bioethics, National Institutes of Health (Bethesda, MD)

**Brian L. Mishara**, Director, Centre for Research and Intervention on Suicide, Ethical Issues, and End-of-Life Practices (CRISE), Université du Québec à Montréal (Montréal, QC)

**Tanya Park**, Assistant Professor, Faculty of Nursing, University of Alberta (Edmonton, AB)

**Suzanne Stewart**, Director, Waakebiness-Bryce Institute for Indigenous Health, University of Toronto (Toronto, ON)

The CCA also recognizes the important contributions of **Yves Beauchamp**, Vice-Principal, Administration and Finance, McGill University (Montréal, QC).

## Message from the Chairs

Medical assistance in dying (MAID) has been a topic of public debate in Canada for over 50 years. In 2015, the Supreme Court of Canada opened a new chapter in the debate with its *Carter* ruling, which was followed 18 months later by the passage of Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. This unprecedented change in the legal landscape — welcomed by some and repudiated by others — reflects an evolving conversation about death and dying that is uniquely Canadian. This conversation continues through the work of the Expert Panel on Medical Assistance in Dying, convened by the Council of Canadian Academies (CCA).

It has been a privilege to serve over the past 18 months as Chairs. More than 40 experts from Canada and abroad, with diverse disciplinary and professional backgrounds, were convened as the Expert Panel while an additional 35 national and international experts served as independent Report Reviewers. The Panel undertook an evidence-based assessment of the state of knowledge surrounding three topics specified in the Act for independent review: MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition. The three reports reflect a broad range of knowledge, experience, and perspective among relevant healthcare professions, diverse academic disciplines, advocacy groups, Indigenous Elders, and from regions where MAID is permitted.

The Expert Panel's work could not have been accomplished without the time and dedication of so many. First, we would like to thank the Panel members themselves, whose exceptional commitment and expert contributions ensured a fair assessment of the evidence. We would also like to express our gratitude to the Report Reviewers, whose detailed and constructive comments improved the depth and quality of each report. Special thanks go to the 59 groups and organizations across Canada affected by or involved in MAID, which responded to our Call for Input and submitted evidence, insight, and stories to enrich the Panel's work. Finally, on behalf of all Panel members, we would like to thank the CCA staff, who worked tirelessly to bring their tremendous research expertise, professionalism, dedication, and good humour to this project, under the guidance of Dr. Eric Meslin, CCA President and CEO.

These reports reflect a particular moment in Canada’s history, in the breadth and availability of evidence, and in the evolution of thinking and practice related to MAID. We invite the Canadian public as well as Parliamentarians to engage in a wider discussion about MAID in the weeks and months following release of these reports. It is our hope that the Panel’s reports will foster this Canadian conversation.

With our thanks for this opportunity to serve,



**Marie Deschamps, C.C., Ad. E.**

Chair, Expert Panel on Medical Assistance in Dying



**Dawn Davies**

Chair, Expert Panel Working Group on MAID for Mature Minors



**Jennifer L. Gibson**

Chair, Expert Panel Working Group on Advance Requests for MAID



**Kwame McKenzie**

Chair, Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition

## Message from the President and CEO

Every CCA assessment focuses on a topic of importance to the Sponsor who requested it and to those who await the Expert Panel's findings. Each is unique in its own way. But when the Minister of Health and Minister of Justice referred MAID-related questions to the CCA, we knew we were undertaking one of our most challenging assignments. For obvious reasons, policy topics about how people live and die are especially difficult because they speak to fundamental concepts of human dignity, autonomy, liberty, and suffering; they remind us of long-standing conversations and debates about the rights of patients and the duties of clinicians; and they reflect diverse social norms and cultural perspectives. With respect to MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition, the task is especially daunting given that domestic and international experience is limited and the existing published literature cannot provide a complete picture of MAID as experienced by patients, families, communities, and healthcare practitioners.

This assessment required care, sensitivity, and wisdom to identify what is known and what gaps in knowledge remain to be filled. While no assessment can include every possible perspective, the CCA was mindful of the need to gather abundant expertise for this project: we invited specialists with clinical, legal, and regulatory expertise to the table; we sought authoritative scholars and practitioners from the fields of law, medicine, nursing, mental health, bioethics, anthropology, and sociology; and we included input from Indigenous elders. Drawing on experts from across Canada and other countries, the CCA established a panel of 43 individuals who together reflected the breadth of knowledge and experience required to answer the Sponsors' questions.

Leadership for this Expert Panel was provided by the Honourable Marie Deschamps, our overall Panel Chair, and by three Working Group Chairs: Dr. Dawn Davies, Prof. Jennifer Gibson, and Dr. Kwame McKenzie. I am grateful to all four Chairs for their dedication and commitment to ensuring these reports reflect the considered views and deliberations of Panel members. I am particularly appreciative of the commitment of every Panel member, each of whom volunteered their time in the service of this important task.

I also wish to express sincere thanks to the three Academies — the Royal Society of Canada, the Canadian Academy of Engineering, and the Canadian Academy of Health Sciences — for their support and expert assistance; to the CCA’s Board of Directors and Scientific Advisory Committee for their advice and input; and to our dedicated staff for their hard work in support of the Expert Panel.

Finally, I would like to thank the Minister of Health and Minister of Justice for entrusting the CCA with the responsibility to undertake an assessment of such importance to Canada and Canadians. The products of the Expert Panel’s work are now in the hands of the Government of Canada, as requested, and will be widely disseminated. It is our hope that this assessment will inform policy discussion and public discussion in Canada and abroad.

A handwritten signature in black ink, appearing to read "Eric M. Meslin". The signature is fluid and cursive, with a prominent initial "E" and a long, sweeping underline.

**Eric M. Meslin, PhD, FCAHS**

President and CEO, Council of Canadian Academies

## **Acknowledgements**

Over the course of its deliberations, the Panel reached out to many individuals and organizations that provided valuable evidence, information, and assistance in the development of the reports. The Panel wishes to thank the following people for their participation in an early planning meeting: Jeff Blackmer, Canadian Medical Association; Jennifer A. Chandler, University of Ottawa; Dawn Davies, University of Alberta; Jocelyn Downie, C.M., FRSC, FCAHS, Dalhousie University; Catherine Frazee, O.C., Ryerson University; Jennifer L. Gibson, University of Toronto; Jean Gray, C.M., FCAHS, Dalhousie University; Douglas Ruth, FCAE, University of Manitoba; Janet Storch, University of Victoria; and Randi Zlotnik Shaul, The Hospital for Sick Children.

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## Report Review

These reports were reviewed in draft form by reviewers selected by the CCA for their diverse perspectives and areas of expertise.

The Report Reviewers assessed the objectivity and quality of the reports. Their submissions — which will remain confidential — were considered in full by the Panel, and many of their suggestions were incorporated into the reports. They were not asked to endorse the conclusions, nor did they see final report drafts before release. Responsibility for the final content of these reports rests entirely with the authoring Expert Panel Working Group and the CCA.

The CCA wishes to thank the following individuals for their review of these reports:

### Reviewers of the MAID for Mature Minors Report

**Priscilla Alderson**, Professor Emerita of Childhood Studies, University College London (London, United Kingdom)

**Cécile Bensimon**, Director, Ethics and Professional Affairs, Canadian Medical Association (Ottawa, ON)

**Marie-Claude Grégoire, FRCPC**, Physician, Perioperative Anesthesiology Clinical Trials Group (PACT), IWK Health Centre; Assistant Professor, Dalhousie University (Halifax, NS)

**Irma Hein**, Child and Adolescent Psychiatrist; Senior Researcher, De Bascule Academic Centre for Child and Adolescent Psychiatry (Amsterdam, the Netherlands)

**Stan Kutcher, FCAHS**, Professor of Psychiatry, Dalhousie University (Halifax, NS)

**Aria Laskin**, Lawyer (Vancouver, BC)

**Constance MacIntosh**, Associate Professor and Viscount Bennett Professor of Law, Schulich School of Law, Dalhousie University (Halifax, NS)

**Chantelle Richmond**, Professor and Canada Research Chair in Indigenous Health and Environment, Western University (London, ON)

**Erica K. Salter**, Associate Professor, Health Care Ethics and Pediatrics, Saint Louis University (St. Louis, MO)

**Hal Siden**, Medical Director, Canuck Place Children's Hospice and BC Children's Hospital (Vancouver, BC)

**Sigrid Sterckx**, Professor of Ethics and Social & Political Philosophy, Ghent University (Ghent, Belgium)

## Reviewers of the Advance Requests for MAID Report

**B. Lynn Beattie**, Professor Emerita, Department of Medicine, University of British Columbia (Vancouver, BC)

**Gina Bravo**, Professor, Université de Sherbrooke (Sherbrooke, QC)

**Catherine Frazee, O.C.**, Professor Emerita, Ryerson University (Toronto, ON)

**Linda Ganzini**, Professor of Psychiatry and Medicine, Oregon Health & Science University (Portland, OR)

**Chris Gastmans**, Professor, University of Leuven (Leuven, Belgium)

**Rosie Harding**, Chair in Law and Society, Birmingham Law School, University of Birmingham (Birmingham, United Kingdom)

**Philip Hébert**, Professor Emeritus, Department of Family & Community Medicine, University of Toronto (Toronto, ON)

**Janet Storch**, Professor Emeritus, University of Victoria (Victoria, BC)

**Tamara Sussman**, Associate Professor, McGill University (Montréal, QC)

**Nele van den Noortgate**, Head, Geriatric Department, Ghent University Hospital (Ghent, Belgium)

**Eric Wasylenko**, Medical Director, Health System Ethics & Policy, Health Quality Council of Alberta; Clinical Associate Professor, Division of Palliative Medicine, Department of Oncology, Cumming School of Medicine, University of Calgary (Calgary, AB)

## Reviewers of the MAID Where a Mental Disorder Is the Sole Underlying Medical Condition Report

**Kenneth Chambaere**, Assistant Professor, End-of-Life Care Research Group, Vrije Universiteit Brussels and Ghent University (Brussels, Belgium)

**Marianne Dees**, Senior Researcher, Department of Primary and Community Care, Radboud Institute for Health Sciences, Radboud University Medical Centre (Nijmegen, the Netherlands)

**Judy Illes, FRSC, FCAHS**, Professor of Neurology and Canada Research Chair in Neuroethics, University of British Columbia (Vancouver, BC)

**Rod McCormick**, Professor and BCIC Chair in Indigenous Health, Thompson Rivers University (Kamloops, BC)

**Bregje Onwuteaka-Philipsen**, Professor of End-of-Life Research, Department of Public and Occupational Health, Amsterdam University Medical Centre (Amsterdam, the Netherlands)

**Elizabeth Peter**, Professor, Lawrence S. Bloomberg Faculty of Nursing and Joint Centre for Bioethics, University of Toronto (Toronto, ON)

**Geoffrey Reaume**, Associate Professor, Critical Disability Studies Graduate Program, York University (Toronto, ON)

**Tom Shakespeare**, Professor of Disability Research, University of East Anglia (Norwich, United Kingdom)

**Scott Theriault**, Deputy Head, Department of Psychiatry, Dalhousie University (Halifax, NS)

**Amy Zarzeczny**, Associate Professor, University of Regina (Regina, SK)

Special thanks are extended to **David Orentlicher**, Cobeaga Law Firm Professor of Law and Co-Director, University of Nevada – Las Vegas William S. Boyd School of Law (Las Vegas, NV) and **Joris Vandenberghe**, Psychiatrist, University Hospitals UZ Leuven and Professor, University of Leuven – KU Leuven (Leuven, Belgium).

### **Report Review Monitors**

The report review procedure was monitored on behalf of the CCA's Board of Directors by three members of the CCA's Scientific Advisory Committee. The MAID Where a Mental Disorder Is the Sole Underlying Medical Condition report review was monitored by **David Castle**, Vice-President Research, University of Victoria; the Advance Requests for MAID report by **Malcolm King, FCAHS**, Professor, University of Saskatchewan; and the MAID for Mature Minors report by **Stuart MacLeod, FCAHS**, Professor Emeritus (Pediatrics), University of British Columbia.

The role of the report review monitor is to ensure that the Panel gives full and fair consideration to the submissions of the reviewers. The CCA Board authorizes public release of an expert panel report only after the report review monitors confirm that the CCA's report review requirements have been satisfied. The CCA thanks Drs. Castle, King, and MacLeod for their diligent contributions as report review monitors.

## List of Acronyms and Abbreviations Used in the Reports

<b>ACP</b>	Advance Care Planning
<b>AED</b>	Advance Euthanasia Directive
<b>CAMAP</b>	Canadian Association of MAID Assessors and Providers
<b>CAMH</b>	Centre for Addiction and Mental Health
<b>CAYAC</b>	Child and Youth Advisory Council at the Alberta Children’s Hospital
<b>CCB</b>	Consent and Capacity Review Board of Ontario
<b>CFCEE</b>	Commission fédérale de Contrôle et d’Évaluation de l’Euthanasie (Belgium)
<b>CNCE</b>	Commission Nationale de Contrôle et d’Évaluation (Luxembourg)
<b>CPS</b>	Canadian Paediatric Society
<b>CPST</b>	Continuous Palliative Sedation Therapy
<b>CSPCP</b>	Canadian Society of Palliative Care Physicians
<b>DSM-5</b>	Diagnostic and Statistical Manual of Mental Disorders, 5 <sup>th</sup> Edition
<b>EAS</b>	Euthanasia and Assisted Suicide
<b>IRER</b>	Immigrant, Refugee, Ethnocultural, and Racialized
<b>MAID MD-SUMC</b>	Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition
<b>NVVP</b>	Nederlandse Vereniging voor Psychiatrie (Dutch Psychiatric Association)
<b>PAD</b>	Physician Aid in Dying
<b>PAS</b>	Physician-Assisted Suicide
<b>PPC</b>	Pediatric Palliative Care
<b>RTE</b>	Regionale Toetsingscommissies Euthanasie (Regional Euthanasia Review Committees), the Netherlands
<b>SCEN</b>	Steun en Consultatie bij Euthanasie in Nederland (Support and Consultation on Euthanasia in the Netherlands)
<b>SDM</b>	Substitute Decision Maker
<b>SLK</b>	Levensindekliniek (End-of-Life Clinic), the Netherlands
<b>VPS</b>	Vulnerable Persons Standard
<b>VSED</b>	Voluntary Stopping of Eating and Drinking
<b>VVP</b>	Vlaamse Vereniging voor Psychiatrie (Flemish Psychiatric Association)

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# 1

## Introduction

- **The Charge**
- **Scope**
- **The Expert Panel**
- **Terminology**
- **Evidence Considered**
- **How to Read this Report**

## 1 Introduction

Canada has become one of a small number of jurisdictions to allow some form of medical assistance in dying (MAID). The Supreme Court of Canada's *Carter v. Canada* decision in 2015 held that an absolute prohibition against physician-assisted death was unjustifiable (SCC, 2015). The landmark ruling was followed by the passage of Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. The Act amended the *Criminal Code* to allow for the provision of MAID under specific circumstances (GC, 2016).

The passage of the Act and the practice of MAID in Canada, however, have not settled public debate. Among the issues under discussion are eligibility criteria and procedural safeguards in the legislation, including the criteria that people under the age of 18 are not eligible for MAID; that it is not possible for a person to consent to MAID through an advance request; and that very few people with a mental disorder as their sole underlying medical condition will meet eligibility criteria for MAID (e.g., that natural death must be reasonably foreseeable). Parliament has called for one or more independent reviews to study the question of prohibiting or permitting MAID to people in the above groups (Section 9.1 of the Act).

To meet their obligation, the Ministers of Health and Justice, on behalf of Health Canada and the Department of Justice Canada (the Sponsors), asked the Council of Canadian Academies (CCA) to conduct independent, evidence-informed reviews of the state of knowledge on MAID as it relates to these three topic areas (mature minors, advance requests, and where a mental disorder is the sole underlying medical condition). The reviews were initiated with a public announcement in December 2016.

### 1.1 THE CHARGE

The objective of the reviews, herein referred to as the *reports*, was to gather and assess information and evidence relevant to the three topic areas in order to inform a national dialogue among the Canadian public, and between the public and decision-makers. The Sponsors therefore asked the CCA to answer the following general questions:

#### Main Question

*What is the available evidence on, and how does it inform our understanding of, medical assistance in dying (MAID) in the case of mature minors, advance requests, and where mental illness is the sole underlying medical condition, given the clinical, legal, cultural, ethical, and historical context in Canada?*

## General Sub-Questions

*What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID for the three topic areas?*

*What are the potential impacts on society of permitting or prohibiting requests for MAID for the three topic areas?\**

*What are the potential risks and safeguards that might be considered related to MAID for the three topic areas?*

*What are the relevant gaps in domestic and international knowledge and research related to MAID for the three topic areas?*

\*E.g., Suicide prevention strategies and medical responses; availability and efficacy of palliative care; dementia-related and mental health services and supports; risks to vulnerable populations; discrimination and stigma related to chronological age, dementia and related illnesses, and mental illness; and risks of inducements.

The charge also included sub-questions specific to the three topic areas:

### Requests for MAID by Mature Minors

*What is the impact of chronological age on the legal capacity to request and consent to MAID?*

*What are the unique considerations related to mature minors requesting MAID (e.g., mature minors vs. adults and MAID vs. other healthcare decisions)?*

### Advance Requests for MAID

*How is an advance request for MAID similar to or different from advance directives for healthcare under existing provincial/territorial regimes?*

*What are the unique considerations to be taken into account depending on when an advance request is made?\*\*\**

\*\*\* That is: 1) before diagnosis; 2) after diagnosis but before onset of suffering; 3) after all of the eligibility criteria and procedural safeguards have been met, except for the 10 day waiting period and the reconfirmation immediately prior to provision of MAID.

### Requests for MAID Where Mental Illness Is the Sole Underlying Medical Condition\*\*\*

*What is the impact of mental illness in its different forms on an individual's legal capacity to request and consent to MAID?*

*What are the unique considerations related to individuals living with mental illness (including mature minors) requesting MAID where the mental illness is the sole underlying medical condition?\*\*\*\**

\*\*\* For certainty, the study is concerned with requests where mental illness is the sole underlying medical condition and does not include circumstances where a person with a mental illness is eligible under the existing law.

\*\*\*\* Both in communities or institutions.

## 1.2 SCOPE

The reports address the questions set out in the charge. They focus on what is known and not known about MAID as it relates to mature minors, advance requests, and a mental disorder as the sole underlying medical condition. The reports do not provide recommendations to governments. It is also important to note that the reports do not evaluate the provisions enacted by Canada's MAID legislation; a formal review of MAID is required at year five (see Section 10 of the Act). Nor do they revisit the legal arguments and evidence for allowing or prohibiting MAID in general.

## 1.3 THE EXPERT PANEL

To address its charge, the CCA assembled a multidisciplinary panel of 43 experts from Canada and abroad (the Panel), divided into three Working Groups. Each Working Group focused on one of the three topic areas. The Panel's expertise covered academic, clinical, legal, and regulatory fields from the disciplines of medicine, nursing, law, bioethics, psychology, philosophy, epidemiology, anthropology, and sociology. Each member served on the Panel on a *pro bono* basis as an informed individual, rather than as a representative of a particular community, discipline, organization, or region. The Panel met in person six times from May 2017 through to July 2018 at various locations across Canada. Panel members convened both in plenary and within their respective Working Groups to deliberate over the evidence.

The Panel also organized three parallel sessions to discuss aspects of the charge that intersected with more than one topic area. These sessions examined the social determinants of health relevant to all three topic areas, the relationship between advance requests and mental disorders, and the intersection between mental disorders and mature minors. The result of these sessions informed each of the reports. The Working Groups and various subgroups also held discussions via teleconference as required to advance the reports between in-person meetings.

## 1.4 TERMINOLOGY

### Medical Assistance in Dying

For the purposes of the reports, and consistent with the federal legislation, the Panel uses the term *medical assistance in dying (MAID)*, which, as defined in the legislation, means:

- (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or
- (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

(GC, 2016)

The gathered evidence often used alternative words and phrases, including *euthanasia*, *assisted suicide*, *physician-assisted suicide*, *physician-assisted death*, or *medical aid in dying*. When referring to evidence from other jurisdictions, the reports use the terminology common to the relevant jurisdiction. A table of legal terminology with notes on common usage in other regions is available in Appendix A.

### Mature Minor

A *minor* is a person under the age of majority (18 or 19 depending on the province or territory). A *mature minor* is a minor who has the capacity to understand and appreciate the nature and consequences of a decision. The Panel's use of further terminology and nuances related to minors, such as *children*, *adolescents*, *youth*, and *adults*, are explained in *The State of Knowledge on Medical Assistance in Dying for Mature Minors*.

### Advance Requests for MAID and Advance Directives

The Panel defines an *advance request for MAID (AR for MAID)* as a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under the circumstances outlined in the request after the person has lost decisional capacity.

ARs for MAID should be distinguished from provincially and territorially regulated *advance directives*, which are documents that “allow a decisionally-capable individual either to designate someone to make decisions about health care on his or her behalf, or to specify types of treatment to be accepted or rejected, should the need arise, or both,” in the event that the individual loses decision-making capacity (Gilmour, 2017). This report explores in detail the possible relationship between advance requests for MAID and advance directives.

## Mental Disorder and Mental Illness

MAID legislation and the charge use the term *mental illness*. However, the Working Group chose to use the term *mental disorder* to be consistent with current clinical and legal practice. *Mental disorder* is the term used in the two primary classification systems in psychiatry: the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems (ICD-10)* (WHO, 2016) and the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (APA, 2013).

### 1.5 EVIDENCE CONSIDERED

The CCA has a long-established approach for convening experts and assessing evidence. Throughout the assessment process, the Panel was asked to identify the range of knowledge and evidence relevant to the charge, examine this body of evidence, and interpret it in the form of findings. The Panel recognizes that the breadth of experience is limited, as a small number of jurisdictions permit some form of MAID and fewer still permit MAID in the three topic areas.

Given the complex, interdisciplinary nature of the topics, the Panel recognized the importance of interpreting evidence broadly and included empirical evidence such as peer-reviewed research and grey literature, normative evidence such as bioethical argumentation, and other forms of evidence such as lived experiences. To this end, the Panel identified and assessed evidence that was found in, but was not limited to, peer-reviewed publications from health disciplines, ethics, social sciences, humanities, and law; professional standards and guidelines; regulatory, legislative, and compliance materials; policy documents; and media reports.

Panel members identified evidence in multiple ways. For example, they drew on their respective disciplinary expertise to identify important evidence in their fields, conducted literature searches, and reviewed responses from the CCA's Call for Input (Section 1.5.1). Evidence gathering also included conversation with Indigenous Elders (Section 1.5.2). Literature searches were carried out using search terms that reflected the diversity of terminology that describes MAID domestically and internationally (Appendix A), as well as related concepts and practices. Literature searches were iterative, informed by Panel deliberations, and included examining literature cited by relevant articles and reports.

The Panel acknowledges a number of challenges and limitations associated with assessing evidence from such diverse sources. In addition to varying quality and availability of research, disciplines may also differ in the evidentiary standards

they apply and in the methods of establishing those standards. It was important, therefore, for the Panel to consider the value and quality of the evidence from the standards of their respective disciplines.

The Panel also recognizes that different types of evidence are not necessarily commensurable, and cannot be ordered within a single hierarchy of credibility. Ethical argumentation, empirical medical research, traditional knowledge, and lived experiences, for example, each give understanding, perspective, and nuance to MAID-related issues that no one type of evidence can provide on its own. Moreover, the Panel recognizes that not all questions that matter can be addressed by empirical research; in some cases, an anecdote conveying meaning through lived experience or an argument based on logic may be more relevant to the question.

To the extent that the evidence allowed, the Panel also considered how MAID legislation regarding the three topic areas might impact diverse groups of people. Panel deliberations therefore considered gender, race, ethnicity, ability, socio-economic status, and other factors affecting the determinants of health, including healthcare access and delivery of services.

The reports are a synthesis of knowledge available to the Panel through the academic and policy literature, the CCA's Call for Input, and its diverse interdisciplinary and professional expertise. The Panel's findings provide a lens into what is currently known about MAID with respect to the three topics at issue. They also shed light on relevant values for MAID policy in Canada, including how differences in values may lead to differences in the interpretation of evidence. The final text is the product of a collective effort to engage with these evidentiary and evaluative inputs to address the charge questions. Each report reflects the general view of its Working Group members even if on some points unanimity could not be established. In some situations, even after consideration of available data and Panel discussions, agreement could not be achieved and significant differences of opinion remained, reflecting the complex and conflicted nature of the issues being reviewed; in those instances, such disagreement is reflected in the reports.

### **1.5.1 Call for Input**

As part of the Panel's evidence-gathering activity, a Call for Input was carried out by the Panel over a three-month period beginning in July 2017. In addition to inviting written input from 500 groups and organizations across Canada affected by, or involved in, MAID, the Call for Input was made available online to any interested organizations. Specifically, the Panel asked organizations to: (i) describe their main issues concerning requests for MAID in the three topic

areas under study; and (ii) submit, or provide links to, any knowledge they would like the Panel to consider. The CCA received 59 submissions from a wide variety of organizations in the areas of advocacy, medicine, nursing, pharmacy, social work, law, and religion (Box 1.1).

Call for Input submissions were shared with Panel members and reviewed to identify issues related to the three topic areas. Call for Input submissions also identified a range of evidence, including professional guidelines and codes of ethics, additional peer-reviewed articles, surveys of membership of professional bodies, and lived experience testimony, not previously available to, or identified by, the Panel. Where relevant, these sources were included in the body of evidence assessed by the Panel.

### **1.5.2 Indigenous Elders Circle**

An Elders Circle, facilitated by Indigenous Panel members, was held in February 2018 to provide insight into Indigenous perspectives on MAID, particularly with respect to the three topic areas. Six Elders from Métis and First Nations in British Columbia, Saskatchewan, Manitoba, and Ontario offered their knowledge of end-of-life attitudes, practices, issues, and concerns. Notably, the Elders felt that Indigenous Peoples had not been consulted on the issue of MAID. The Panel recognizes that the Elders Circle was limited in scope and representation, and does not constitute consultation with Indigenous Peoples on the topic of MAID. This remains a significant knowledge gap.

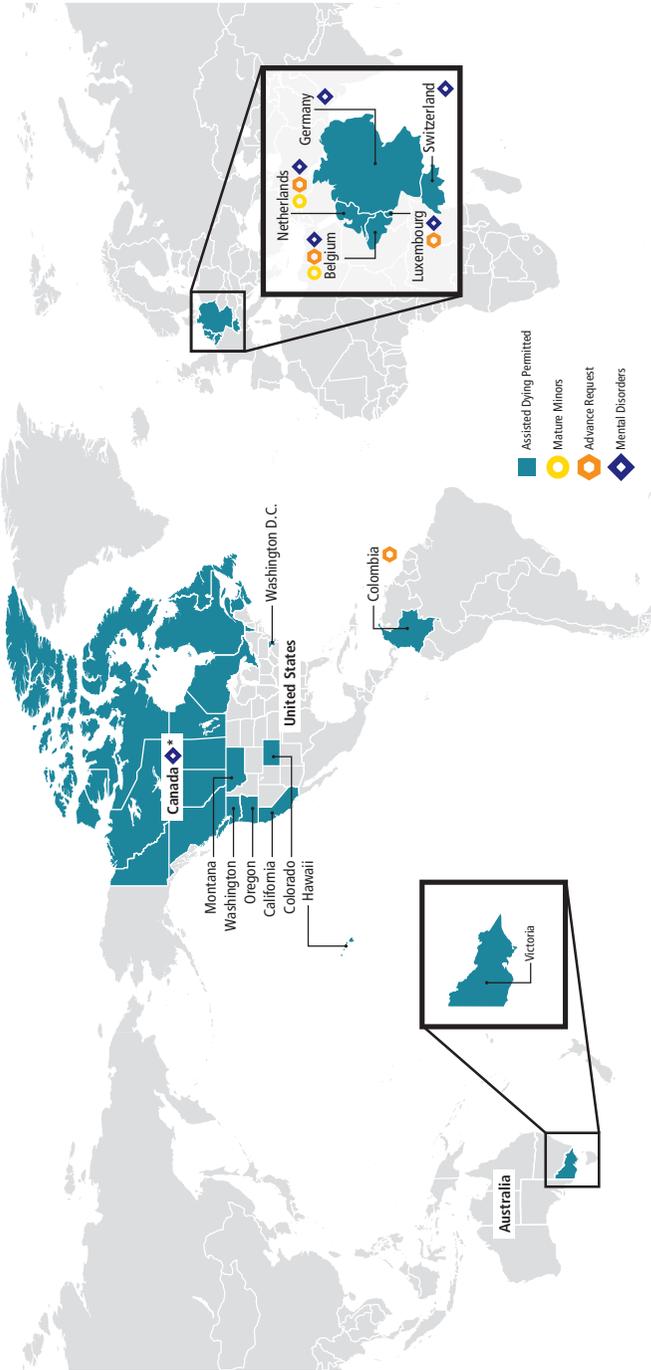
### **1.5.3 International Experience**

The Panel considered the experiences and evidence from other countries that allow some form of assisted dying. In cases where access to relevant documents from other countries was impeded by language, professional translators were engaged.

Assisted dying is legal or partially decriminalized in a small number of jurisdictions (Figure 1.1); areas that allow assisted deaths do so with specific access criteria and safeguards. The Panel considered and assessed critically the international evidence in light of the Canadian healthcare environment, its unique geography and history, and the contemporary political and social policy context within which the MAID conversation is occurring.

**Box 1.1****Organizations That Made a Formal Submission to the CCA's Call for Input**

- Addictions and Mental Health Ontario
- Alberta College of Social Workers
- Alzheimer Society of British Columbia
- Alzheimer Society of Nova Scotia
- Association for Reformed Political Action
- Association médicale du Québec
- Association of Registered Nurses of British Columbia
- Autism Canada
- British Columbia College of Social Workers
- British Columbia Humanist Association
- Canadian Association for Community Living
- Canadian Association of MAID Assessors and Providers
- Canadian Bar Association
- Canadian Coalition for the Rights of Children
- Canadian Federation of Catholic Physicians' Societies
- Canadian Medical Association
- Canadian Medical Protective Association
- Canadian Mental Health Association
- Canadian Physicians for Life
- Canadian Psychiatric Association
- Canadian Society of Palliative Care Physicians
- CARP
- Catholic Civil Rights League
- Catholic Health Alliance of Canada
- Centre for Addiction and Mental Health
- Christian Legal Fellowship
- Christian Medical and Dental Society of Canada
- Collège des médecins du Québec
- College of Licensed Practical Nurses of Manitoba
- College of Physicians and Surgeons of Ontario
- College of Registered Nurses of Manitoba
- College of Registered Psychiatric Nurses of Manitoba
- Community Health Nurses of Canada
- Covenant Health
- Dying with Dignity Canada
- Empowerment Council
- Evangelical Fellowship of Canada
- Federation of Medical Regulatory Authorities of Canada
- Institut de planification des soins
- Manitoba Provincial MAID Clinical Team
- National Association of Pharmacy Regulatory Authorities
- Nova Scotia College of Pharmacists
- Nurse Practitioner Association of Canada
- Nurse Practitioner Association of Manitoba
- Ontario College of Social Workers and Social Service Workers
- Ontario Psychiatric Association
- Ontario Shores Centre for Mental Health Sciences
- Ottawa Catholic Physicians' Guild
- Physicians' Alliance Against Euthanasia
- REAL Women of Canada
- Right to Die Society of Canada
- Salvation Army
- St. Joseph's Health Care London
- The Hospital for Sick Children
- Toronto Catholic Doctors' Guild
- Toujours Vivant-Not Dead Yet
- University Health Network
- University of Toronto Joint Centre for Bioethics MAID Implementation Task Force, MAID Advance Request Working Group
- West Coast Assisted Dying



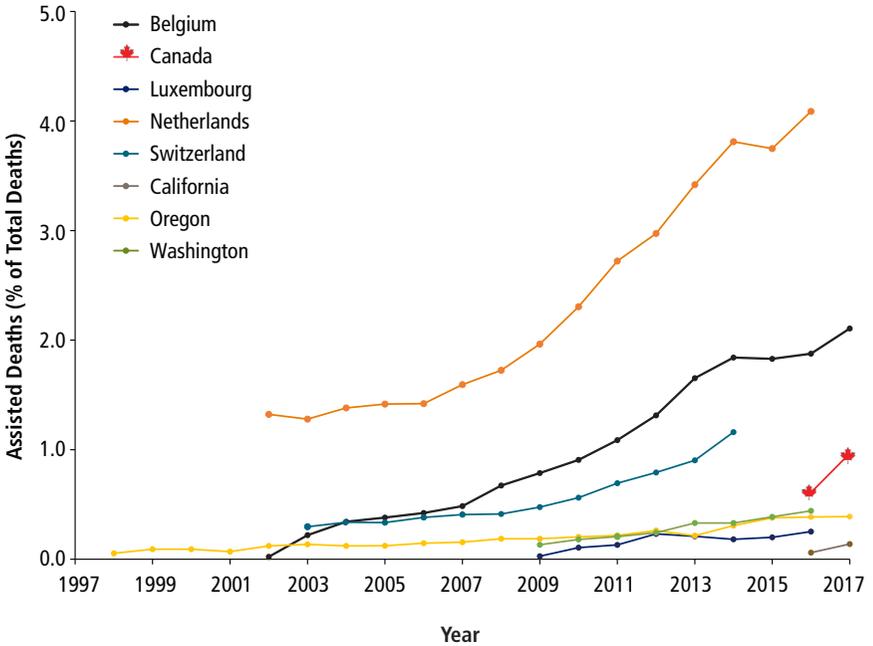
Data Source: Bruns, 2016; GC, 2016; Gov. of Belgium, 2002; Gov. of CA, 2015; Gov. of CO, 2016; Gov. of DC, 2016; Gov. of Germany, 1998; Gov. of HI, 2018; Gov. of Luxembourg, 2009; Gov. of the Netherlands, 2002; Gov. of OR, 1997; Gov. of Switzerland, 1942; Gov. of VT, 2013; Gov. of WA, 2009; Supreme Court of the State of Montana, 2009

**Figure 1.1 Map of the World Showing Places Where Some Form of Assisted Dying is Allowed**

This figure represents the understanding of the Expert Panel regarding the status of assisted dying worldwide, given the available knowledge at the time this report was written. Jurisdictions vary in terms of the legal mechanism by which assisted dying is allowed (e.g., through legislation or a court decision), the form of assisted dying that is permitted (e.g., self-administration or physician administration of a lethal substance), and the specific eligibility criteria (e.g., requirement of a terminal illness or a minimum age). For additional information, see Appendix A. The symbols on the map indicate the countries in which assisted dying can be accessed by mature minors, through advance requests, or by people with a mental disorder as their sole underlying medical condition.

\*To access assisted dying in Canada, including for a mental disorder, death must be reasonably foreseeable, but this is not a requirement in Belgium, Luxembourg, or the Netherlands.

Rates of uptake vary considerably among, and even within, regions; in U.S. states, which only allow self-administration by patients with a diagnosis of terminal illness, the proportion of deaths attributed to physician-assisted suicide remains under 1% (Figure 1.2). The Panel notes that data collection and reporting procedures vary substantially both within and among jurisdictions. Relevant details and discussion of evidence from foreign jurisdictions are included in the body of the reports.



Data Source: Belgium Belgium (CFCEE, 2004, 2006, 2008, 2010, 2012, 2014, 2016, 2018; SB, 2018); Canada (GC, 2017a, 2017b, 2018b; StatCan, 2018); Luxembourg (CNCE, 2017; Gov. of Luxembourg, 2018); Netherlands (RTE, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012b, 2013, 2014a, 2015d, 2016c, 2017d; CBS, 2018; RTE, 2018b); Switzerland (Gov. of Switzerland, 2018b, 2018a); California (Gov. of CA, 2017, 2018); Oregon (Gov. of OR, 2018a, 2018b); Washington: (Gov. of WA, 2018b, 2018c)

Figure 1.2

**Reported Assisted Deaths as a Percentage of Total Deaths per Year by Location**

Not all locations where some form of assisted dying is permitted publicly report the number of such deaths each year; data presented in the figure are the best available at this time. Note that assisted dying practices vary among U.S. states; data from individual states are presented where available.

### 1.5.4 Knowledge Gaps

Direct evidence on the practice of assisted dying in the three topic areas is limited to publicly available documentation from the few countries that allow assisted dying for mature minors, through advance requests, or where a mental disorder is the sole underlying medical condition. However, many of the questions and issues related to the three topic areas identified by the Panel do have an evidence base, often spanning multiple disciplines including law, ethics, medicine, nursing, psychology, psychiatry, and sociology. This evidence forms the core of what the Panel assessed. There are nonetheless knowledge gaps for these issues; where they exist, the Panel identified and factored them into its findings.

## 1.6 HOW TO READ THIS REPORT

This report is one of three related reports that collectively examine the evidence related to medical assistance in dying: MAID for Mature Minors, Advance Requests for MAID, and MAID Where a Mental Disorder Is the Sole Underlying Medical Condition. Though each report is authored by a different Working Group of the Expert Panel, the three reports have been developed in parallel and benefitted from common discussions across the Working Groups.

These reports can therefore be read independently or as a single body of work. To support this structure the three topic area reports share the same first two chapters: Chapter 1: *Introduction* and Chapter 2: *MAID in Canada: Historical and Current Considerations*. These two chapters provide common information and context relevant to all three reports. The chapters that follow comprise the core of the topic area assessment. Chapters 3 through 5 present context, issues, and evidence specific to the respective topic area. Chapter 6 is a discussion of potential impacts, implications, and safeguards. Each report concludes with its own Chapter 7, which provides summary answers to the charge.

# 2

## **MAID in Canada: Historical and Current Considerations**

- **How Did We Get Here?**
- **Implementation of MAID in Canada**
- **Provision of Healthcare in Canada**
- **Healthcare Decision-Making**
- **Chapter Summary**

## **2 MAID in Canada: Historical and Current Considerations**

The partial decriminalization of MAID in Canada followed a succession of legal challenges, societal and technological changes, advocacy and scholarly work, and public and professional discussions, some of which began more than 50 years ago. The Panel understands that MAID is a deeply personal topic about which there are differing views on the relevant evidence, and that one's perception about the need for the practice to include mature minors, advance requests, or where a mental disorder is the sole underlying medical condition is informed by life experiences, values, and beliefs. Moreover, Panel members, regardless of their own disciplinary expertise, recognize that clinical, ethical, legal, and societal considerations may be in tension with one another. This chapter provides a context for current discussions of MAID in Canada with the understanding that these discussions will continue to evolve.

The chapter begins with an overview of some pivotal points in this history, along with certain contemporary realities of delivering healthcare services in a culturally diverse and geographically expansive country. The three topic areas also touch on several common considerations — informed consent, decision-making capacity, and decision-making authority — each of which is discussed in the context of MAID in Canada. Given the breadth and complexity of issues, the chapter seeks to provide the reader with a common starting point for thinking about MAID in the three topic areas. It does not purport to be a definitive or comprehensive examination of the historical, social, and political context of MAID in Canada.

### **2.1 HOW DID WE GET HERE?**

The public conversation in Canada about end-of-life decision-making dates back more than half a century. The development of new life-prolonging technology and medical interventions prompted conversations about their use and/or withdrawal among patients, families, clinicians, and institutions. Arnup (2018), citing Smith and Nickel (2003), points out that healthcare in Canada in the post-war years featured new technologies and focused on saving lives, and that “little thought was given to dignity, pain relief or quality of care” of the dying. By the late 1960s, however, the palliative care and hospice movements began to take hold, based on the idea that patients at the end of life required equal clinical attention — albeit of a different kind — even when cure was no longer possible (Mount, 1976; Saunders, 2001; Arnup, 2018). High-profile cases, such as that of Karen Ann Quinlan in the United States, brought public attention to end-of-life discussions about cessation of treatment and quality of life (Martin, 2016).

In 1982, the Law Reform Commission of Canada published a working paper, followed in 1983 by a full report, entitled *Euthanasia, Aiding Suicide and Cessation of Treatment* (LRCC, 1982, 1983). The Commission recommended against decriminalization or legalization of euthanasia or assisted suicide, but did make recommendations to clarify the legal right of a patient to refuse treatment and of a physician to cease treatment that has become therapeutically useless and is not in the best interests of the patient (LRCC, 1983). Nine years later, the decision in the case of Nancy B. in Quebec City affirmed a capable patient's right to refuse life-sustaining treatment even if such a decision led to death (QCCS, 1992).

### 2.1.1 Sue Rodriguez Challenges the Assisted Suicide Prohibition in Canada

In the early 1990s, Sue Rodriguez, a woman with amyotrophic lateral sclerosis (ALS), applied to the Supreme Court of British Columbia to have the *Criminal Code* prohibition on assisted suicide declared unconstitutional. After the British Columbia Supreme Court dismissed her application, Ms. Rodriguez appealed to the British Columbia Court of Appeal and, after being unsuccessful there, to the Supreme Court of Canada (SCC, 1993).

The key constitutional rights implicated by the prohibition on assisted suicide were Sections 7 and 15(1) of the Canadian *Charter of Rights and Freedoms* (GC, 1982). Section 7 states that everyone has “the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” Section 15(1) states that every person has the right to “equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.” While actions taken by governments are subject to these provisions, Section 1 of the Charter states they may limit rights insofar as such limits are “reasonable,” “prescribed by law,” and “demonstrably justified in a free and democratic society.” Ms. Rodriguez argued that she would be unable to take her own life without assistance when she no longer had the capacity to enjoy life because of her disease. Ms. Rodriguez stated that, since suicide is legal under the *Criminal Code*, prohibiting assisted suicide discriminates against people with a physical disability that makes them incapable of taking their own life (SCC, 1993).

On September 30, 1993, the Supreme Court of Canada ruled, by a five-to-four majority, that the prohibition against assisted suicide was in accordance with the principles of fundamental justice and as such did not violate Section 7 of the Charter. The Supreme Court also concluded that a violation of Section 15(1) of the Charter would be “demonstrably justified in a free and democratic society” and ruled that the prohibition was constitutional (SCC, 1993).

### 2.1.2 Public Conversation, Consideration, and Study

Discussions of choice at end of life did not stop after the *Rodriguez* decision. Following a series of papers published by the Canadian Medical Association on assisted suicide and euthanasia in 1993, the Senate of Canada appointed a Special Committee in 1994 to “examine and report on the legal, social and ethical issues relating to euthanasia and assisted suicide” (SSCEAS, 1995). The Committee heard testimony and reviewed letters and briefs from across Canada for 14 months, before publishing a final report in 1995, with a majority recommending against changing the legal status of euthanasia and assisted suicide in Canada (SSCEAS, 1995).

Criminal cases reported in the media across Canada in the 1990s, such as those of Robert Latimer in Saskatchewan and Dr. Maurice G n reux in Ontario, inspired further public and private debate (see Deschamps, 2017 for a review of cases). Moreover, Canadians were not insulated from highly publicized international cases, such as those of Dr. Jack Kevorkian in the United States (Martin, 2016). Advocacy groups, such as Dying with Dignity Canada and its Quebec counterpart, Association qu b coise pour le droit de mourir dans la dignit , campaigned for choice at end of life in Canada. Within clinical practice, discussions of appropriate end-of-life care practices and policy development were ongoing (e.g., CFPC, 2012; CMA, 2014).

Academic study of the issues of euthanasia and assisted suicide by scholars in Canada from a range of disciplines, including law, bioethics, philosophy, and history, informed perspectives about the practice (e.g., Somerville, 2001; Downie, 2004; Dowbiggin, 2005; Sumner, 2011). In 2011, the Royal Society of Canada published a multidisciplinary review of end-of-life decision-making that included research on assisted death (RSC, 2011).

In recent decades, legislative attempts to amend the *Criminal Code* to permit euthanasia and/or assisted suicide in limited circumstances were unsuccessful. These attempts came from diverse political parties: Svend Robinson (New Democratic Party, 1992, 1994), Francine Lalonde (Bloc Qu b cois, 2005, 2008, 2009), Stephen Fletcher (Conservative Party, 2014), and Nancy Ruth (Conservative Party, 2014) (Butler *et al.*, 2013; Deschamps, 2017).

### 2.1.3 Quebec Enacts End-of-Life Legislation that Includes Medical Aid in Dying

In 2006, Quebec’s medical regulator, Coll ge des m decins du Qu bec (CMQ), embarked on a three-year process to study appropriate care at the end of life (CMQ, 2009). In November 2009, a working group report concluded that, despite advances in palliative care, there were exceptional cases in which clinical

interventions were ineffective and, in those situations, a patient would have no option but to suffer until death (CMQ, 2009); this position was subsequently adopted by the CMQ (Robert, 2010). In December 2009, the National Assembly of Quebec unanimously adopted a motion to create a select committee of members to study the issue of dying with dignity (Gov. of QC, 2012).

Reporting to the National Assembly in March 2012, the committee noted that opinion had shifted in public polls in support of euthanasia and assisted suicide, and among healthcare practitioners in surveys conducted by professional associations (Gov. of QC, 2012). In June 2014, the Quebec government passed *An Act Respecting End-of-Life Care* (Gov. of QC, 2014), which took effect in December 2015. This Act addresses patients' entitlement to receive the full spectrum of care at the end of life, and includes medical aid in dying. The Quebec eligibility criteria and safeguards are similar, but not identical, to those of the federal statute (Gov. of QC, 2014).

#### **2.1.4 Carter v. Canada Overturns the Blanket Prohibition on Assisted Suicide**

In 2011, two family members of Kay Carter (a woman with spinal stenosis who had travelled to Switzerland for an assisted suicide), William Shoichet (a medical doctor willing to participate in physician-assisted deaths), and Gloria Taylor (a woman with ALS) joined with the British Columbia Civil Liberties Association to challenge federal prohibition on physician-assisted dying. In 2015, the Supreme Court of Canada concluded that the challenged provisions of the *Criminal Code* were void insofar as:

[T]hey prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.

(SCC, 2015)

In contrast to the five-to-four decision in *Rodriguez v. Canada* (1993), the *Carter* decision was unanimous (9-0); the decision stated that a blanket prohibition on assisted suicide deprives adults of the right to life, liberty, and security of the person. For the purposes of the reports, it is important to note that *Carter* considered the case of adults with decision-making capacity, and that it made “no pronouncement on other situations where physician-assisted dying may be sought” (SCC, 2015). The Supreme Court confirmed at the same time the role of the criminal law, suspending the declaration of invalidity of the criminal prohibition for one year to allow time for a legislative and regulatory response to the judgment (SCC, 2015).

### 2.1.5 Bill C-14 and the Partial Decriminalization of MAID

In response to the *Carter* ruling, after study and consultation (e.g., PTEAG, 2015; SJCPAD, 2016), the federal government introduced Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. The Act received Royal Assent on June 17, 2016, creating the federal statutory framework for MAID (GC, 2016).

The preamble to the federal MAID legislation takes into consideration the autonomy and intolerable suffering of persons with grievous and irremediable medical conditions who wish to seek MAID; the need for “robust safeguards ... to protect against errors and abuse;” affirmation of the “inherent and equal value of every person’s life” and the avoidance of “negative perceptions of the quality of life of persons who are elderly, ill, or disabled;” the protection of vulnerable persons from “being induced, in moments of weakness, to end their lives;” and the recognition that “suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities” (GC, 2016). The preamble concludes:

permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable strikes the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other.

A specific concern of the legislators, as evidenced in the preamble to the Act, was a possible impact of MAID on suicide rates and suicide prevention. Suicide is not a criminal offence in Canada, but assisting a person to end their life is illegal unless the conditions of the MAID legislation are met (GC, 2016). In addition to being a public health issue, suicide prevention is also foundational to the practice of mental health services. Suicide, suicide prevention, and the possible impacts of MAID laws are discussed in detail in Sections 3.2 and 4.2 in *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*.

The legislation provides eligibility criteria and procedural safeguards to establish the parameters of legally permissible MAID in Canada (Box 2.1).

**Box 2.1****Eligibility Criteria for Accessing MAID in Canada**

**241.2 (1)** A person may receive medical assistance in dying only if they meet all of the following criteria:

- (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;
- (c) they have a grievous and irremediable medical condition;
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

**241.2 (2)** A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

- (a) they have a serious and incurable illness, disease or disability;
- (b) they are in an advanced state of irreversible decline in capability;
- (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

(GC, 2016)

Two independent medical or nurse practitioners must be of the opinion that the person requesting MAID meets all of the eligibility criteria. Furthermore, there must be 10 clear days between the formal request and the provision of MAID, unless the person's death or loss of capacity is imminent. Immediately prior to the provision of MAID, the person must be given an opportunity to withdraw their request and must give express consent to the procedure (GC, 2016).

Thus, mature minors under the age of 18 are not eligible for MAID; competent persons cannot provide valid consent by means of an advance request for MAID; and competent persons with a mental disorder as their sole underlying medical condition will rarely meet all of the eligibility criteria.

## **2.2 IMPLEMENTATION OF MAID IN CANADA**

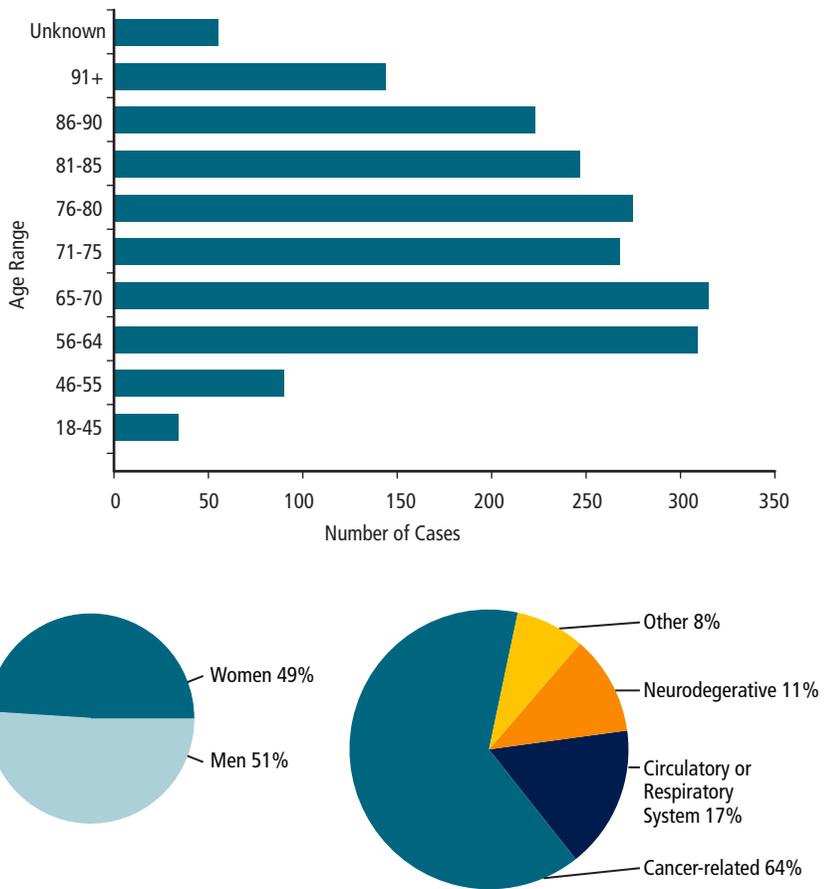
The best available data indicate that 3,714 people in Canada accessed MAID between December 10, 2015 and December 31, 2017 (GC, 2018b). This number includes data from Quebec (but only until June 9, 2017), and excludes data from Yukon, Northwest Territories, and Nunavut. In 2017, MAID deaths represented approximately 1% of all deaths in Canada (GC, 2018b).

The most common underlying conditions among those who received MAID in 2017 (n=1,961)<sup>1</sup> were cancer (64%), followed by diseases of the circulatory/respiratory system (17%), and neurodegenerative conditions (11%); 51% of recipients were men and 49% women. People ranged in age from 18–45 to over 90 years old, with the largest demographic being 65–70 years of age (Figure 2.1).

New federal monitoring regulations, introduced July 25, 2018, specify reporting requirements and designate a recipient to receive reports from medical and nurse practitioners and pharmacists in each province and territory (GC, 2018a). Prior to the introduction of federal monitoring regulations, Health Canada produced three interim reports based on available data from the provinces and territories (GC, 2017a, 2017b, 2018b).

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1 Excludes data from Yukon, Northwest Territories, Nunavut, and Quebec.



Data Source: GC, 2018b

Figure 2.1

**Characteristics of Reported MAID Deaths in Canada in 2017**

MAID deaths in Canada, as reported to Health Canada in 2017, by age, gender, and underlying medical condition. The figure excludes data from Yukon, Northwest Territories, Nunavut, and Quebec.

In Quebec, *An Act Respecting End-of-Life Care* legislated the creation of a commission that submits an annual activity report, no later than September 30, to the Minister of Health and Social Services (Gov. of QC, 2014). Since its inception, the Commission has published two reports, the first in October 2016 (Gov. of QC, 2016) and the second in October 2017 (Gov. of QC, 2017c). Additionally, executive directors of health and social services institutions, as well as the CMQ (which collects reports directly from individual private practice physicians), are required to publicly report on numbers of MAID requests and outcomes (GC, 2018b).

### 2.2.1 Pending Legal Challenges to MAID Legislation

The British Columbia Civil Liberties Association and Julia Lamb, a 25-year-old woman with spinal muscular atrophy (a progressive degenerative condition), filed a constitutional challenge to the federal Act on June 27, 2016 (BCCLA, 2016). The lawsuit challenges eligibility criteria (reasonably foreseeable death, incurable illness or condition, advanced state of irreversible decline), arguing that the federal legislation unjustifiably limits Sections 7 and 15 of the Charter and is not saved by Section 1 (BCCLA, 2016).

In Quebec, in June 2017, Jean Truchon, a 49-year-old man with cerebral palsy, and Nicole Gladu, a 71-year-old woman with post-polio syndrome, filed a legal challenge against the assisted dying laws in Canada and Quebec (QCCS, 2017b). They argue that the eligibility criteria in the legislation (“natural death has become reasonably foreseeable” and “end of life”) are too restrictive, violate Sections 7 and 15 of the Charter, and cannot be saved under Section 1.

Also in Quebec, Paul Saba, a physician, has variously challenged the validity of the Quebec statute on assistance in dying and the federal MAID law on several bases, including that the current deficiencies in healthcare services prevent patients from giving informed consent. He also claims that the regime is unconstitutional and goes against Quebec’s *Code of Ethics of Physicians* and the *Canada Health Act* (QCCS, 2017a).

In a statement of claim filed with the Ontario Superior Court of Justice, Roger Foley, who has a serious neurological disability, claims that the defendants (his local hospital, local health integration network, and others) have violated his Charter rights by failing to provide adequate and appropriate home care services to relieve his suffering. Additionally, he claims the defendants have offered to provide assisted suicide instead of an assisted life. He also seeks, in part, a declaration that the MAID provisions in the *Criminal Code* are unconstitutional and therefore invalid (ONSC, 2018).

### 2.2.2 Legal Interpretations of MAID Legislation

In 2017, the Ontario Superior Court of Justice made an *interpretive declaration* regarding the eligibility criterion of a reasonably foreseeable death in the discussion of a case involving a patient seeking MAID (*AB v. Canada (Attorney General)*). Referring to the language used in Canada’s MAID legislation, the Court stated:

This language reveals that natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan.

(ONSC, 2017)

The College of Physicians and Surgeons of Nova Scotia has similarly provided a broad interpretation of reasonable foreseeability in its *Professional Standard Regarding Medical Assistance in Dying*, referencing the *AB v. Canada (Attorney General)* case (CPSNS, 2018). Furthermore, an Inquiry Committee for the College of Physicians and Surgeons of British Columbia found a woman had met MAID eligibility criteria “despite the fact that her refusal of medical treatment, food, and water undoubtedly hastened her death and contributed to its ‘reasonable foreseeability’” (CPSBC, 2018).

The College of Physicians and Surgeons of Ontario has two policies requiring physicians who conscientiously object to MAID to make an effective referral for patients who request MAID (CPSO, 2015a, 2016). Several groups and individual physicians challenged these policies, stating they violate one’s right to freedom of religion, freedom of conscience, and right to equality. The Ontario Superior Court of Justice (Divisional Court) decided on January 31, 2018 that any infringement on physicians’ freedom of religion was justified given its objective of ensuring equitable access to healthcare (ONSCDC, 2018). An application for leave to appeal was filed in the Ontario Court of Appeal on February 20, 2018 (Golding & Rosenbaum, 2018).

### 2.2.3 MAID Delivery and Regulation

MAID is an exemption in the *Criminal Code* to criminal offenses of homicide and assisted suicide, as long as specific eligibility criteria are met and certain safeguards are followed (Box 2.1). Debates about eligibility criteria for MAID include debates about the scope of criminal law, the prohibitions on causing death that the criminal law contains, and the social norms represented therein. However, MAID is also a medical act, regulated and delivered through the healthcare system, as, by law, only medical and nurse practitioners can provide MAID in Canada. Thus, a brief overview of MAID delivery and regulation in the healthcare system follows.

Provinces and territories are primarily responsible for delivering healthcare services to their residents; however, the federal government has responsibility in providing primary healthcare to certain groups (GC, 2012a). Provincial and territorial healthcare legislation defines the obligations of health authorities, healthcare institutions, and individual practitioners with respect to the delivery of healthcare services. These obligations are set out in legislation regulating, for example, hospitals (e.g., Gov. of NS, 1989) and healthcare consent (e.g., Gov. of ON, 1996). In the case of Quebec, provincial legislation regulates end-of-life care, including MAID (Gov. of QC, 2014). Subsequent to the passage of the federal MAID legislation, Manitoba and Ontario introduced or amended statutes to address implementation (e.g., Gov. of MB, 2017; Gov. of ON, 2017a).

Provincial and territorial legislation establishes regulatory colleges that enforce standards of practice and regulate the conduct of professional healthcare providers, such as nurses, physicians, and pharmacists. Colleges enforce standards through the licensing and disciplining of professional members; their purpose is to serve and protect the public, ensuring competency and quality of practice within their professions (e.g., Gov. of BC, 1996c). Quebec has legislation defining codes of ethics for specific professions, such as physicians (Gov. of QC, 2017a). Many regulatory colleges have developed professional standards and policies for the assessment and provision of MAID by their members (e.g., CPSO, 2016; CPSNS, 2018; CRNBC, 2018).

Hospitals also regulate the practices provided by their institutions and within their facilities, including the provisioning of MAID. There may be public and independent health facilities regulated by different pieces of legislation within a province or territory (e.g., Gov. of ON, 1990a, 1990b, 1990c). Physicians, in law, are generally treated as independent contractors; however, hospitals exert control over the professional conduct of physicians, for instance, by granting or revoking privileges to provide care in their facility. Hospitals hold the authority to hire and regulate the conduct of other healthcare professionals, such as nurses and pharmacists. Many hospitals have developed policies to regulate the provision of MAID (e.g., TOH, 2016).

Professional associations and societies, such as the Canadian Association of MAID Assessors and Providers (CAMAP), the Canadian Society of Palliative Care Physicians (CSPCP), and the Canadian Nurses Association, are organizations of healthcare practitioners and scholars. These organizations seek to provide support, information, and guidance to healthcare practitioners, but do not license members and do not have regulatory authority.

### 2.2.4 End-of-Life Practices Other than MAID

Though MAID is a novel practice in Canada, subject to eligibility and safeguards prescribed by the *Criminal Code*, it is implemented in a healthcare context where long-standing end-of-life practices exist, such as withdrawing or withholding treatment, continuous palliative sedation therapy, and abstaining from nutrition and hydration. This section briefly reviews their legal status in Canada.

#### Withdrawing or Withholding Life-Sustaining Treatment

Under Canadian law, people with decision-making capacity clearly have the right to refuse treatment even where that refusal will result in their death (QCCS, 1992). There is no formal requirement in law that refusals be well considered or settled. Mature minors and individuals with a mental disorder who have decision-making capacity may choose to withdraw or withhold life-sustaining treatment, as may their substitute decision makers (SDMs), should they later lose decisional capacity.

Refusals of treatment can be expressed through an advance directive, which may be in the form of written instructions or a chosen SDM. An SDM appointed by operation of a statute (e.g., family member) may decide, on behalf of a patient who lacks decision-making capacity, to withdraw or withhold life-sustaining treatment if they believe it is in accordance with the patient's wishes (where known), or the best interests of the patient (where the patient's prior capable wishes are not known) (see Section 3.3.2).

#### Continuous Palliative Sedation Therapy (CPST)

The Canadian Medical Association defines CPST as “complete sedation, with the intent of rendering the patient unable to experience the environment, sensation or thoughts, until the patient dies naturally from the underlying illness” (CMA, 2017b). CPST is clearly legal when it does not cause death — that is, when delivered in combination with cessation of artificial hydration and nutrition where death is anticipated within approximately 48 hours (Downie, 2017). Where death is anticipated within two weeks, CPST with the provision of artificial hydration and nutrition is clearly legal (again, it does not cause death) (Downie, 2017). In practice, CPST is generally done without artificial hydration and nutrition. Where death is anticipated within 14 days, the legal status of CPST in combination with cessation of artificial hydration and nutrition is less clear (Downie, 2017); however, it is arguably legal (Downie, 2018). Where death is not anticipated for some time, the legal status of CPST in combination with cessation of artificial hydration and nutrition is unclear.

### Voluntary Stopping of Eating and Drinking (VSED)

Some patients choose to stop eating and drinking, knowing they will die as a result. Competent patients can refuse oral hydration and nutrition (e.g., holding a glass to a person's lips, spoon-feeding) and artificial hydration and nutrition (e.g., intravenous fluids, feeding tube), and advance directives (where applicable in Canada) may also include refusal of artificial hydration and nutrition (Downie, 2017). In some provinces (e.g., Nova Scotia), oral hydration and nutrition can also be refused through advance directives; however, this is less clear in some other provinces (e.g., BCCA, 2015).

VSED has been used in Canada as a pathway to eligibility for MAID. If one stops eating and drinking, their natural death becomes reasonably foreseeable (or, in Quebec, the person reaches their "end of life"). For example, a Quebec man refused food for 53 days and water for 8 days in order to become eligible for MAID (McKenna, 2016). Similarly, a woman in British Columbia refused food and water for 14 days in order to become eligible to receive MAID (CPSBC, 2018).

## 2.3 PROVISION OF HEALTHCARE IN CANADA

As a first point of contact, primary healthcare services offer immediate care for health problems, routine care, or health information. Family physicians, nurse practitioners, pharmacists, and telephone advice lines can provide these kinds of services. Primary healthcare also provides coordination of specialized services, such as specialist consultation and care (e.g., cardiologists, allergists, psychiatrists) or care provided in hospitals (GC, 2012b).

In 2013, about 29% of people in Canada aged 15 or older reported difficulty in accessing healthcare services, most commonly due to wait times or difficulty securing appointments (Clarke, 2016). In 2016, 15.8% of those aged 12 or older reported that they did not have a regular healthcare provider<sup>2</sup> (StatCan, 2017a). Men aged 18 to 34 were the most likely group to report not having a regular healthcare provider (approximately 33%), whereas men and women over the age of 65 were the least likely group (6.5% of men and 5.3% of women). Self-identified Indigenous people were more likely to report not having a primary healthcare provider (19.2%) compared to the rest of the population (15.8%) (StatCan, 2017). Large geographic distances among communities and low population densities make healthcare more costly in remote areas, resulting in reduced access to services and professionals; this is most pronounced in northern parts of Canada, where visiting professionals or locums provide many

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2 Estimates exclude the territories, because the survey did not cover all communities in 2016.

key health services periodically on a short-term basis (NCCAH, 2010). To receive specialized care, patients are often required to leave their home communities by flying to more densely populated centres (NCCAH, 2010; MacIntosh, 2017).

With respect to end of life, access to palliative care also varies across Canada. Access to palliative care and coverage of services such as pharmaceuticals, home care, psychologists, and residential long-term care exist piecemeal across provinces and territories, and are funded through a mix of public programs, private insurance, and out-of-pocket payments by individuals (Carstairs, 2010; Chappell & Hollander, 2011; Verma *et al.*, 2014). Gaps in existing data present challenges in understanding the full extent of this issue (Canadian Cancer Society, 2016). An oft-cited statistic notes that only 16 to 30% of people in Canada have access to palliative care (Carstairs, 2010), though it is based on a study of in-hospital palliative care in Western Canada only (Downie & Lloyd-Smith, 2014). Barriers to access include issues of training and education among healthcare professionals, such as the lack of adequate training in palliative care in Canada (Stonebridge, 2017). In a letter to the Quebec Health Minister dated May 29, 2018, the CMQ raised concerns that, because palliative care and social services are increasingly diverted to those who make a request for MAID, patients may seek to access these services by requesting MAID (CMQ, 2018).

### 2.3.1 Health and Health Equity in Canada

There are significant disparities in health in Canada. For example, life expectancy is consistently lower than average in regions with high unemployment rates, lower educational achievement, and greater material and social deprivation (PHAC, 2018). Low socio-economic status is also related to higher incidences of chronic disease, such as arthritis, asthma, and diabetes (PHAC, 2018). Studies have demonstrated that immigrant, racialized, and ethnocultural groups face barriers in accessing physical and mental healthcare (McKenzie *et al.*, 2016). Disparities in preventive care such as reduced access to breast cancer screening or mental healthcare, as well as outcomes of care such as lower cancer survival rates, have been reported (Booth *et al.*, 2010; Kumachev *et al.*, 2016; McKenzie *et al.*, 2016).

Such systemic factors (or social determinants of health) are estimated to influence up to 60% of a population's health status (CMA, n.d.). Healthcare access can explain up to 25% of a population's health status, while biology and genetics account for 15% (CMA, n.d.). Social determinants of health include community, housing, food security, physical environment, gender, ability, race, and Indigenous status, among others (PHAC, 2018).

Social determinants can affect the risk of developing an illness, the course and severity of the illness, and the availability of treatment. Stigma and discrimination influence health outcomes, affecting some groups and individuals differently. People with disabilities and their families have reported, for many years, that the healthcare system makes negative assumptions about the quality of their lives (e.g., Stainton & Besser, 1998; Gill, 2000; Drainoni *et al.*, 2006); some health professionals believe life with extensive disabilities is not worth living (Gill, 2000). The need for improved health equity is a fundamental issue in Canada, increasingly enshrined in provincial and territorial legislation. Improving health equity allows people to achieve their full health potential by removing preventable and avoidable systemic conditions that constrain life choices, including choices at the end of life (e.g., Batavia, 2001).

### 2.3.2 Barriers to Healthcare for Indigenous People

Reconciliation with Indigenous people calls for the provision of services consistent with their cultures and needs. Yet, formal healthcare for Indigenous people in Canada has historically been highly segregated and of low quality (FNHA, 2017; Geddes, 2017). The sharing of responsibilities among federal, provincial, and territorial governments has created a patchwork healthcare system. Payment disputes between federal and provincial/territorial governments can result in delayed access to necessary health services (NCCAH, 2010).

Healthcare inequities experienced by Indigenous people have been well documented (e.g., Loppie *et al.*, 2014; Allan & Smylie, 2015; Hart & Lavallée, 2015; TRC, 2015). Racism continues to create and reinforce disparities (Loppie *et al.*, 2014; Allan & Smylie, 2015), and, as noted in Section 2.3.1, inequitable access to healthcare leads to poor health outcomes (Reading & Wien, 2009). A lack of appropriate and safe healthcare can prevent Indigenous people from seeking treatment (NCCAH, 2010); deficiencies in cultural safety and competence, as well as historical and current abuses, have resulted in some Indigenous people losing trust in the healthcare system (Geddes, 2017). Indeed, the Truth and Reconciliation Commission called for the Canadian healthcare system to recognize the value of Indigenous healing practices and use them when treating Indigenous patients (TRC, 2015).

Indigenous Peoples hold a variety of spiritual views that may inform conceptions of health, death, and dying that are both different from and similar to Western conceptions. Traditional teachings stress the interconnectedness of all of creation, and that humankind is to live in harmony with the natural world (NFB, 2015). In contrast to the positivist (i.e., empirical data-focused) attitudes that dominate modern Western medicine, Indigenous conceptions of health are more holistic in nature (Stewart & Marshall, 2017). For many Indigenous people, connections to family, friends, community, nature, and culture are an

important part of the healing process, suggesting that they may be more receptive to healthcare services based on a theme of interconnectedness (McCormick, 1997). The medicine wheel, for instance, underscores the importance of balance and emphasizes four interrelated forms of health: physical, emotional, spiritual, and mental/intellectual (Dyck, 1996). Some conceptualizations of the medicine wheel also represent the four stages of life in the physical world: birth, youth, adulthood, and death (NLM, n.d.). Many Indigenous people believe in an afterlife and some view the dying process as preparation for the afterlife journey (Kelly & Minty, 2007).

The Indigenous Elders who shared their knowledge and experiences at the Elders Circle (Section 1.5.2) stated that life is sacred and, therefore, death should not be the subject of casual discussion, which risks diminishing life's value. Ideally, individuals make end-of-life decisions as part of a community, embedded in supportive relationships. The Elders felt that allowing MAID for people with mental disorders could be damaging in communities experiencing youth suicide crises. Elders also shared experiences of systemic barriers that prevented them or their loved ones from accurate diagnoses and appropriate treatment. Without basic access to appropriate healthcare and social services in the community, the Elders expressed concern that MAID is a highly inappropriate care option. Consideration of MAID in the three topic areas is a low priority for most Indigenous communities that are also dealing with a lack of clean water, food security, healthcare, and other basic needs. The Elders, while appreciative of the CCA's effort in facilitating the Elders Circle, noted that they do not speak for all Indigenous perspectives. The Panel recognizes that too little input from Indigenous people creates a significant gap in the evidence considered for these reports. It is important to consider the potential needs and concerns of Indigenous Peoples with respect to MAID in the three topic areas.

### 2.3.3 Culture and End-of-Life Care

Family, ethnicity, religion, workplace, education, as well as other factors contribute to one's cultural experience. Culture can be profoundly influential in how people, both patients and healthcare practitioners, view end-of-life medical care, and death and dying in general (Chakraborty *et al.*, 2017). As a result, one's choice in medical treatment is likely affected by one's personal views on death. While discussions on medical options to prolong life may be appropriate and desirable for some, others may view them as an interference in the natural passage of life (Coolen, 2012). In some cultural traditions, suffering is an essential and spiritually meaningful part of life, and something to be experienced and endured rather than avoided (Searight & Gafford, 2005). Lived experience of racism and historical trauma in the healthcare system also play a role in attitudes towards end-of-life care (e.g., Welch *et al.*, 2005).

Religion and spirituality can be especially important when making end-of-life medical decisions (Chakraborty *et al.*, 2017). Religion may play an essential role in providing meaning and insights into issues of health, medicine, death, dying, and philosophies about an afterlife (O’Connell, 1995). There are diverse perspectives among and even within the faith traditions, which are not homogenous (e.g., orthodox or conservative versus reform or liberal perspectives). This diversity of perspective shapes the opinions that religious people may have about MAID.

The diversity of cultural experiences in Canada influences any examination of the impacts and implications of MAID in the three topic areas. A thorough consideration of these perspectives was beyond the scope of the reports and remains a significant knowledge gap.

## 2.4 HEALTHCARE DECISION-MAKING

In Canadian law, respect for a person’s autonomy and the protection of their bodily integrity are the core values underlying the principle that decisions made by capable individuals must be respected, and the more specific rule that consent must be obtained prior to treatment (Gilmour, 2017). There are exceptions to this general rule: for example, in some provinces and territories, refusals made by capable minors (Day, 2007) or by capable adults who are involuntarily committed to hospital because of mental disorders may not be followed (Wildeman, 2016). Discussions of healthcare decision-making occur more specifically in each topic area report, but three decision-making concepts are important to clarify for consistency: informed consent, decision-making capacity (as a clinical and legal concept), and decision-making authority.

### 2.4.1 Informed Consent

Provincial and territorial legislation specifies that informed consent must be:

- related to the proposed healthcare;
- given voluntarily;
- not obtained by fraud or misrepresentation;
- given by a person capable of making the healthcare decision;
- given by a person who has had the opportunity to ask questions about the proposed care and alternatives, and receive answers; and
- given by a person adequately informed to understand the proposed care, including information on the nature of the proposed care, its risks and benefits, and on reasonable alternatives to the proposed care, including non-treatment.

(Gov. of BC, 1996a; Gov. of ON, 1996;  
Gov. of PE, 1988; Gov. of YK, 2003b)

Nova Scotia requires hospitals to obtain informed consent to care for patients; however, this statute does not extend to facilities other than hospitals (Gov. of NS, 1989). Quebec requires physicians to obtain informed consent from patients as stated in the *Code of Ethics of Physicians* (Gov. of QC, 2017a) and established in the *Civil Code of Quebec* (Gov. of QC, 1991). Outside Quebec, common law determines informed consent requirements for provinces and territories that do not have explicit legislation and for practices that are outside the scope of legislation on healthcare consent (Wahl *et al.*, 2014).

### 2.4.2 Decision-Making Capacity

All adults are presumed to have decision-making capacity unless there are reasonable grounds to believe otherwise or unless legislation removes that presumption (Gilmour, 2017). A patient has capacity when they have the ability to understand and appreciate the nature and consequences of their decisions. Capacity refers to the cognitive abilities necessary for sound decision-making — specifically, being able to understand information relevant to making a decision and the ability to appreciate the reasonably foreseeable consequences of a decision (or lack of decision). When questioned, capacity becomes decision- and time-specific; it is assessed in relation to the decision to be made and at the time of its implementation. It is not a global determination of the presence or absence of a person's overall decision-making ability (Gilmour, 2017).

Guidelines, policies, and guidance related to capacity and consent are provided by health regulatory colleges, and in some cases by employers (e.g., hospitals, health authorities), experts, scholars, and organizations such as the Canadian Medical Protective Association (CMPA) (LCO, 2017; CMPA, n.d.). There is no universally accepted clinical approach to capacity assessment (Seyfried *et al.*, 2013) and little data on the assessment of capacity in the specific circumstances of MAID (i.e., in the presence of intolerable suffering) (Cartagena *et al.*, 2016). In determining capacity for clinical decisions, healthcare practitioners typically use either a directed clinical interview or a formal capacity assessment tool such as the MacArthur Competence Assessment Tool (MacCAT) (Grisso *et al.*, 1997) or Aid to Capacity Evaluation (ACE) (Etchells *et al.*, 1999).<sup>3</sup> Formal capacity assessment tools remind clinicians what dimensions of understanding and appreciation to question; it is then up to the clinician to judge whether a person's abilities fulfil (or not) the criteria laid out in law or policy.

Clinicians determine when a capacity assessment is appropriate (Leo, 1999; Ganzini *et al.*, 2004; Dastidar & Odden, 2011), unless a court has already determined a person is legally incompetent or the person is deemed to lack capacity by the operation of a statute. The purpose of a clinical capacity

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3 For a comprehensive list of clinical capacity assessment tools, see Kim (2010).

assessment is to provide a yes/no judgment about whether a specific person can consent to a specific medical treatment (at a specific time, in a specific context) (Charland, 2015).

### 2.4.3 Decision-Making Authority

Adults with decision-making capacity have legal authority over their healthcare decisions. However, the decision-making authority of minors and involuntarily committed patients, regardless of capacity, is constrained in some provinces and territories (for more information see *The State of Knowledge on Medical Assistance in Dying for Mature Minors* and *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*). If an adult is found to lack decision-making capacity, the healthcare practitioner must notify and explain this finding to the individual. The next step is to determine whether there is a valid instruction directive, applicable to the medical decision at hand. The healthcare practitioner must identify (or determine) who the SDM is. That may be someone identified by the patient in a written document prior to losing capacity (i.e., a proxy directive) (Dalhousie Health Law Institute, 2017). The SDM may also be a guardian or person appointed by a statute or court. Some provinces and territories have recognized alternative models to substitute decision-making in limited circumstances, such as supported decision-making (e.g., Gov. of BC, 1996b; Gov. of YK, 2003a; Gov. of AB, 2008a; Gov. of MB, 1993b) and co-decision-making (Gov. of SK, 2000).

If there is no recognized, appointed SDM, most provincial and territorial legislation defines a nearest relative who can act on behalf of the person for the specific treatment decision at hand (e.g., Gov. of BC, 1996a; Gov. of SK, 2015). SDMs act in accordance with the person's prior capable wishes; if unknown, the SDM makes a decision in the person's best interests. See Section 3.3.2 for more information.

## 2.5 CHAPTER SUMMARY

Recent changes in Canadian law have led to the partial decriminalization of MAID. Informed discussions of MAID must consider the complex legislative and regulatory Canadian contexts outlined above, as well as the broader historical context that informs a diversity of perspectives on how best to approach MAID with respect to the three topic areas. The relative significance of healthcare and specialized services regulation, delivery, and access, however, varies across the three topic areas, and considerations of informed consent, decision-making capacity, and decision-making authority will particularly diverge. Indeed, as presented in these reports, MAID as it relates to mature minors, advance requests, and where a mental disorder is the sole underlying medical condition gives rise to distinct issues that interface differently with the various aspects of Canada's healthcare and legal systems.

# 3

## **Advance Requests for MAID: Context and Concepts**

- **What Is an Advance Request for MAID?**
- **Understanding the Interest in and Concerns with Advance Requests for MAID**
- **Consent and Decision Making in Canadian Healthcare**
- **Key Concepts Relevant to Advance Requests for MAID**
- **Chapter Summary**

### 3 Advance Requests for MAID: Context and Concepts

#### Key Findings

An AR for MAID is a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under circumstances outlined in the request after the person has lost decisional capacity.

An AR for MAID operates without requiring express consent at the time of the procedure, which creates uncertainty as to whether the person who made the request desires the procedure at that time.

Allowing ARs for MAID would require reconsideration of what constitutes valid consent in both healthcare and criminal law.

Societal norms around end-of-life care are changing. It is becoming more common to make treatment decisions and document preferences before a loss of decision-making capacity through advance care planning and advance directives. As Canada's population ages, more people will experience capacity-limiting conditions, which will affect the demand and delivery of healthcare resources. ARs for MAID, should they be allowed, would operate in this evolving context.

Allowing or prohibiting ARs for MAID requires policy makers to take a position on the interplay among the concepts of autonomy (individual and relational), suffering (and the intolerability of suffering), and vulnerability (inherent and situational) created by a loss of decision-making capacity.

Legislation in Canada requires that medical and nurse practitioners who provide MAID must “immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying” (GC, 2016). Those who are unable to provide express consent or who do not possess decision-making capacity are ineligible for MAID.

Any person may make a MAID request at any point in time; however, if they do not meet the eligibility criteria, the request will be denied. People may inquire about MAID, have conversations with their physicians or family members, and even begin to prepare the request paperwork before they are eligible to access

the procedure. However, if — based on a patient’s prior directive — a healthcare practitioner provides MAID when that patient lacks the capacity to consent, the healthcare practitioner will be in violation of the *Criminal Code* (GC, 2016).

For ARs for MAID to be permitted under Canadian law, the requirement for express, informed consent immediately prior to the procedure would need to be removed. This might be viewed as in line with how advance decision-making for treatment and care currently operates in Canada. Indeed, the subject of ARs for MAID was much discussed in the lead-up to Bill C-14 (e.g., SSCEAS, 1995; RSC, 2011; EPOLRCC, 2015; PTEAG, 2015; SJCPAD, 2016).

ARs for MAID may create uncertainty for those responsible for following through with the request. While uncertainty is inherent to most decision-making processes, for ARs for MAID, the onus on a third party would be unique: to sanction or take positive actions whose purpose is to cause the death of a patient. In the absence of a requirement for consent at the time of the procedure, the healthcare practitioner, substitute decision maker (SDM), and family members could not be certain that the patient is suffering intolerably and wishes for MAID. This understandably complicates the presumption that ARs for MAID could fit readily into the context of current end-of-life decision-making and healthcare in Canada.

The purpose of this chapter is twofold. First, it examines how ARs for MAID might be situated within the wider context of Canadian healthcare policy, end-of-life decision-making, and societal perspectives. Second, it sets out the main moral dimensions of ARs for MAID that underlie many of the practical and conceptual issues discussed in later chapters.

### 3.1 WHAT IS AN ADVANCE REQUEST FOR MAID?

ARs for MAID currently exist only in concept; there is no definition of an AR for MAID in Canada. For the purposes of this report, therefore, the Working Group defines an AR for MAID as *a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under circumstances outlined in the request after the person has lost decisional capacity*. An AR for MAID is only relevant after the person has lost decision-making capacity. The Working Group makes no assumptions regarding the format, regulation, or timing of such a request.

Note that this report refers to advance euthanasia directives (AEDs) when discussing written euthanasia requests in Belgium, Luxembourg, and the Netherlands, reflecting the terminology used in those jurisdictions.

### 3.1.1 Situating ARs for MAID in the Canadian Healthcare Context

In recent decades, Canada's healthcare system has adopted two approaches relevant to the consideration of ARs for MAID: patient-centred care and advance care planning (ACP). If ARs for MAID were allowed in Canada, they would be situated within these two healthcare approaches, both of which emphasize the value that some people place on defining their wishes and preferences for end-of-life care. ARs for MAID would also exist alongside the practice of advance directives, which have long been used in healthcare to express a patient's wishes for care should they lose the capacity to make decisions for themselves.

#### Patient-Centred Care and ACP

Patient-centred care has been increasingly recognized as a fundamental component of high-quality healthcare in Canada (CMA, 2008; OMA, 2010). It departs from a paternalistic model of care in which the physician represents the final authority in healthcare decisions. While patients cannot demand treatment that is not medically indicated or that is outside the standard of care (CMPA, 2014), a patient-centred approach values communication, partnership, and health promotion — the relationship between the healthcare practitioner and patient is one of collaboration towards the common goal of patient well-being (Constand *et al.*, 2014). Patient-centred care focuses on the patient's preferences and provides timely access to care to address patient needs, regardless of their ability to pay for services (CMA & CNA, 2011).

Over the past 15 years, there has also been a major push to get people thinking earlier about their wishes, values, and preferences as these apply to end-of-life care. ACP is “a process of thinking about and sharing your wishes for future health and personal care” (Speak Up, 2018b). ACP can be informal, such as conversations with family and friends, but can also include formal documentation, such as advance directives. To engage in ACP, people must think about, discuss, and document their wishes for future healthcare in case they lose the capacity to make decisions themselves. ACP involves discussions with loved ones (and sometimes healthcare practitioners or lawyers) about individuals' general preferences related to medical treatment and specific interventions that they would consent to or refuse (e.g., tube feeding) under various circumstances (CHPCA, 2012). A national framework for ACP, published in 2012, is supported by the ongoing work of the Advance Care Planning National Task Group (CHPCA, 2012; Speak Up, 2018a). The Canadian Medical Association, Canadian Nurses Association, and the Canadian Hospice Palliative Care Nurses Group also support the ACP national framework (CNA *et al.*, 2015; CMA, 2017a).

### Advance Directives

If ARs for MAID were allowed in Canada, they would join the collection of different types of personal initiatives that comprise ACP, including advance directives for healthcare. Advance directives are documents that specify treatment preferences (*instruction directives*), designate a trusted person as an SDM (*proxy directives*), or both, in the event a person loses decision-making capacity (Gilmour, 2017). Advance directives are regulated through provincial and territorial legislation (Table 5.1).<sup>4</sup> Healthcare practitioners, in forms such as a Goals of Care Designation (e.g., AHS, 2014) or Do Not Resuscitate (DNR) order, may also document consent or refusal of life-sustaining treatment. Goals of Care and DNR orders are not generally considered advance directives because they are tools used in hospitals by the healthcare team to guide and document discussions of treatment plans (Wahl *et al.*, 2016).

#### Box 3.1

#### Quebec's Advance Directives Registry

In 2014, Quebec passed legislation creating an advance directives registry, with formalized documentation and notarial requirements for healthcare consent surrounding end-of-life decisions by instruction directive (Gov. of QC, 2014). Advance directives are specific to situations at end-of-life, to a loss of capacity due to an irreversible persistent vegetative state, or to a severe and irreversible decline leading to loss of decision-making capacity. In an advance directive, people can consent to (or refuse) cardiopulmonary resuscitation (CPR), mechanical ventilation, or artificial hydration or feeding (Bernier & Régis, 2017). Critiques of the legislation point to the rigidity of the documentation used for anticipating preferences, stating that informed consent is a process involving an understanding of circumstances and relational autonomy that cannot be accurately reflected in a "check list" of options for future care (Bernier & Régis, 2017).

<sup>4</sup> Advance directives are known by a variety of names across Canada (e.g., *healthcare directives* in Manitoba and *personal directives* in Nova Scotia). Instruction directives may, for example, be called *living wills* while proxy directives may, for example, be called *durable powers of attorney for healthcare*.

Measuring how many people in Canada have advance directives is challenging given that each province and territory has its own health legislation and, until recently, none had a registry to track such documents (Box 3.1). Furthermore, as healthcare practices change in response to evolving attitudes and norms, the introduction of new technologies and innovations, and fluctuating healthcare budgets, it is difficult to know how long research and data related to advance directives will be relevant to current practice. These caveats aside, data on the existence and use of advance directives, however dated, may help illustrate broad trends; these data are examined in Chapter 5.

### **3.1.2 Differentiating ARs for MAID from ACP and Advance Directives**

ACP requires people to think about the types of medical treatments that they would prefer to receive or refuse in the future. Advance directives can protect patient autonomy by designating an SDM or documenting wishes, values, and preferences for care in the event of capacity loss. These may include advance consent to, or refusal of, specific treatments or personal care decisions, such as foregoing the use of blood and blood products in accordance with some religious beliefs, requesting (or refusing) resuscitation in the event of cardiac or respiratory arrest, or refusing artificial nutrition and hydration in the event of a permanent loss of consciousness.

The ethical similarity between MAID and the refusal or withdrawal of treatment is questionable and often contested. Respecting patient autonomy recognizes a patient's authority over their bodily integrity and their right to accept or refuse a healthcare intervention (SCC, 2015). A healthcare intervention without consent constitutes assault, except in emergencies where treatment is necessary to preserve life, but where the patient is unable to provide consent and their wishes are not known. For example, a physician might do whatever was necessary to keep someone alive and alleviate pain in an emergency, but would not begin a course of cancer treatment without consent of the patient or their SDM. MAID, however, is an exception to criminal law prohibitions against counselling or aiding suicide and culpable homicide (GC, 2016). Practitioner-administered MAID fundamentally involves invading a person's bodily integrity. That is, an AR for MAID is a request for an intervention that specifically ends the life of another person; some Working Group members therefore argue that it is important to abstain when there is uncertainty about ongoing consent.

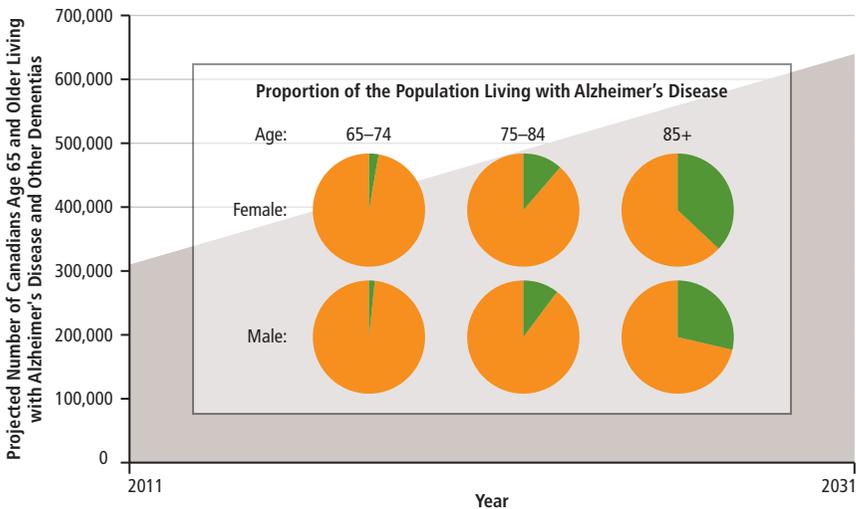
Both advance directives and ARs for MAID can include decisions that result in a person's death. ARs for MAID differ from advance directives in that they inevitably involve a third party who must, based on a documented request, determine the exact timing and circumstances of a person's death. In contrast, advance directives do not compel a third party to decide that another person is ready to die, though the withdrawal or withholding of treatment may certainly result in death.

### **3.2 UNDERSTANDING THE INTEREST IN AND CONCERNS WITH ADVANCE REQUESTS FOR MAID**

As discussed in Section 3.1.1, a shift towards a patient-centred approach to healthcare and the encouragement of ACP reflects the value that some people in Canada place on defining their preferences for end-of-life care. Additionally, Canada's population is aging and, as people live longer, more are living with chronic, progressive conditions, some of which include a prognosis of capacity loss. Such social and demographic shifts influence both the demand for ARs for MAID and the need to protect vulnerable populations while providing quality, accessible care.

#### **3.2.1 Predicted Increase in the Prevalence of Capacity-Limiting Conditions**

The prevalence of neurological conditions is predicted to increase in the adult population over the next 20 years; by 2031, it is estimated that 674,000 people over the age of 40 will be living with Alzheimer's disease and other dementias in Canada (GC & NHCC, 2014). The prevalence of dementia increases substantially with age, and, of those predicted to be living with dementias in 2031, most will be over the age of 65 (GC & NHCC, 2014). Currently, more women than men are aged 85 and over — of the estimated 6,620 centenarians living in Canada in 2017, 89% were women (StatCan, 2017b). Dementia prevalence is also higher in women than in men. As Figure 3.1 illustrates, 37% of women aged 85 and over are living with Alzheimer's disease (Alzheimer Society of Canada, 2016a). Any eligible person with decision-making capacity can request and consent to MAID, including those with a dementia diagnosis, though progressive neurological diseases will eventually result in a loss of decision-making capacity. Section 4.1 provides an overview of the trajectories of the main neurological disorders causing capacity loss.



Data Source: GC & NHCC, 2014; Alzheimer Society of Canada, 2016a

Figure 3.1

### Projected Number of Canadians Age 65+ Living with Alzheimer's Disease and Other Dementias, 2011 and 2031

The background graph illustrates the projected increase in the number of people living with Alzheimer's disease and other dementias in Canada from 2011 to 2031 (GC & NHCC, 2014). The inset pie charts illustrate the proportion of people (in green) living with Alzheimer's disease in different age groups (65-74, 75-84, and 85+ years old), based on 2014 estimates of prevalence (Alzheimer Society of Canada, 2016a).

As the number of people living with capacity-limiting conditions increases, so will the demand for care services (Hermus & Stonebridge, 2017). The prevalence of chronic illness differs by gender, as well as by other factors such as income level and geographic location (e.g., urban versus rural) (PHAC, 2018). A 2007 study of home and long-term care among Ontarians found that women represent a higher proportion of long-stay home care clients; moreover, male clients most commonly reported spouses as their primary caregivers (76% of 20,102 men surveyed) compared to female clients (37% of 51,201 women surveyed) (Gruneir *et al.*, 2013). As the population ages, the healthcare costs of dementia — including financial costs and emotional and social costs related to informal caregiving — will increase over time (Turner & Findlay, 2012; Alzheimer Society of Canada, 2016a; Manuel *et al.*, 2016). In 2012, nearly half of people 15 years and older in Canada had provided care to a family member with a chronic condition due to disease, disability, or aging needs (Sinha, 2013). Those who witness the aging and decline of loved ones

may feel strongly about the value of planning for their own eventual decline, whether or not that includes a request for MAID, particularly after navigating the complex issues associated with making serious decisions on behalf of a loved one who has lost capacity. In the coming years, more people will be making decisions, either for themselves or on behalf of loved ones, informed by the availability and accessibility of end-of-life care options in Canada.

### 3.2.2 Current Opinion on ARs for MAID

Canadian public opinion surveys suggest there is general support for a legal mechanism through which a person can provide advance consent for MAID. In an online poll of 2,066 people comprising a representative sample of the Canadian population recruited by Leger, 62% agreed and 22% disagreed that they should have access to an assisted death if they have advanced dementia and an advance directive indicating their desire for MAID at that stage of the illness (EPOLRCC, 2015). Forum Research (2016) found that 74% of adult respondents (n=2,271, randomly selected by an interactive voice response telephone survey) supported allowing assisted death for people who leave explicit legal instructions for the procedure but who are no longer able to communicate their consent at the time of MAID. In an Ipsos Public Affairs online poll of 2,530 people in Canada, conducted on behalf of Dying with Dignity Canada via the Ipsos I-Say panel, support for an advance consent mechanism for MAID was slightly higher for cases where a person has a grievous and irremediable medical condition at the time the request is made (approximately 80% when a patient has a condition versus 70% when they do not) (Ipsos Public Affairs & Dying with Dignity Canada, 2016).

### 3.2.3 Government-Commissioned Reports that Examined ARs for MAID

Two reports commissioned by governments following the *Carter* decision in Canada argued in support of ARs for MAID. The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (PTEAG-PAD) recommended that ARs for MAID be legally permissible for people diagnosed with a grievous and irremediable condition (PTEAG, 2015). The Advisory Group reasoned that denying an AR for MAID to those with a neurodegenerative condition might drive some people to suicide prior to capacity loss, resulting in fewer potential good years of life due to fear of intolerable suffering at the end. The Advisory Group also recommended further study of requests made by people before any medical diagnosis, as members could not reach an agreement on the topic (PTEAG, 2015). These recommendations represented an attempt to reconcile diverse views to advise policy-makers as they developed legislation, and were not representative of the views of individual group members (PTEAG, 2015).

After considering testimony and published briefs (including the PTEAG-PAD report), the Special Joint Committee on Physician-Assisted Dying recommended that ARs be permitted for MAID (SJCPAD, 2016). Specifically, the Committee suggested that they be permitted at any point after someone is “diagnosed with a condition that is reasonably likely to cause loss of competence or after a diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable” (SJCPAD, 2016). The Committee acknowledged the challenge of ensuring advance consent is adequately informed, but prioritized limiting suffering for those diagnosed with a condition that would cause capacity loss (SJCPAD, 2016). It also included a dissenting minority report cautioning against the recommendation to allow ARs for MAID, recommending instead that more time be devoted to exploring the legal and policy implications (SJCPAD, 2016).

### **3.2.4 Advocacy Positions on ARs for MAID**

Advocacy organizations differ with respect to their positions on ARs for MAID; this diversity was reflected in the submissions to the CCA’s Call for Input. For example, the Alzheimer Society of Canada does not support advance consent for MAID for people with dementia (Alzheimer Society of Canada, 2016b). Provincial chapters of the Alzheimer Society, however, expressed no specific position for or against ARs for MAID in submissions to the Call for Input, instead highlighting the need to include the voices of people living with dementia and their families and caregivers in the discussion (Alzheimer Society of British Columbia, 2017; Alzheimer Society of Nova Scotia, 2017). In contrast, Parkinson Canada “supports the use of advanced consent for medical assistance in dying when suffering becomes intolerable later in the disease course whether or not the person has competency” (Parkinson Canada, 2016).

In its submission to the Call for Input, Dying with Dignity Canada, an advocacy association that promotes the protection of end-of-life rights, stated that it supports ARs for MAID in part because of its concern about persistent suffering in people with advanced dementia (Dying with Dignity Canada, 2017a). However, the Canadian Association for Community Living, which promotes the social inclusion of people with intellectual disabilities, suggests that lack of support and access to quality care motivate ARs for MAID “because of fears of not getting adequate care or becoming burdens on others” (CACL, 2017).

### 3.3 CONSENT AND DECISION MAKING IN CANADIAN HEALTHCARE

MAID is an exemption to homicide and assisted suicide in the *Criminal Code* when practised by medical and nurse practitioners adhering to specific criteria. As such, there would be a significant legal context were ARs for MAID to operate in Canada. This section examines briefly some elements of valid consent in healthcare and criminal law in Canada, and describes how healthcare decisions are made when a patient does not possess decision-making capacity.

#### 3.3.1 Perspectives on Consent and Advance Consent in Canadian Law

From a legal standpoint, consent is central to healthcare decision-making. Without consent to treatment, interference with bodily integrity is an assault (GC, 1985a); thus, healthcare practitioners who provide treatment or procedures without patient consent might expose themselves to civil or criminal liability (CMPA, 2016b).

Healthcare consent must be informed. Some provincial and territorial legislation defines the elements of informed consent, and these elements are consistent in common law. Informed consent must be voluntary, related to the proposed healthcare, and expressed by a person capable of making a reasonable decision based on truthful and adequate information provided by the healthcare practitioner (Gov. of PE, 1988; Gov. of BC, 1996a; Gov. of YK, 2003b). Requirements for informed consent, however, do not apply in medical emergencies where treatment decisions are necessary to save the patient from death or severe injury, but the patient's wishes are unknown; however, the physician must respect the patient's wishes as soon as they are made known (Evans, 2016).

Another aspect of healthcare consent is that it can be either implied or expressed (Evans, 2016). Making an appointment, keeping the appointment, answering a physician's questions, and volunteering information all contribute to an implied consent to examination. For more invasive, painful, or risky treatment options, expressed consent becomes necessary to protect both the clinician and patient. Expressed consent may be given in writing (e.g., signing a consent form prior to surgery) or orally (e.g., spoken agreement to a treatment plan) (Evans, 2016).

ARs for MAID are, in themselves, an expression of consent to MAID created in advance of a loss of decision-making capacity. Advance consent may be a familiar concept to healthcare practitioners thanks to instruction directives or consent to surgery forms. Advance consent to (or refusal of) healthcare is largely regulated through provincial and territorial legislation, and can be as legally effective as present consent to (or refusal of) healthcare. For example, Prince Edward Islands's *Consent to Treatment and Health Care Directives Act (1988)* states: "A decision contained in a directive shall be as effective as if made by the maker when the maker had capacity to make the decision" (Gov. of PE, 1988). Case law also establishes respect for advance refusal of treatments (e.g., *Malette v. Shulman* (1990), discussed in Section 5.2.1). However, even where an instruction directive exists, in the experience of the Working Group's clinical members, confirmation of consent is sought prior to initiation of treatment from the patient's SDM or family members (Figure 3.2).

Advance consent is also common in the context of medical research, whereby written advance directives are used as guides in the consent process; however, the active participation of the person who lacks legal capacity is still sought to the extent possible (CIHR *et al.*, 2014). Physical dissent on the part of the incapacitated person precludes participation, regardless of any written directive. Additionally, the consent of an authorized third party is required before those who lack decision-making capacity can participate in research, regardless of the presence of a research directive (CIHR *et al.*, 2014).

In criminal law, the validity of advance consent is complex and variable. For example, in the case of *R. v. J.A.* (2011), the Supreme Court of Canada ruled that one could not consent to sexual activity that occurs while a person is unconscious (SCC, 2011). Consent requires a conscious, operating mind, and there is no substitute for present consent to sexual activity at the time it occurs (SCC, 2011). Consent to a fistfight was not found to be a valid defence for assault in the case of *R. v. Jobidon* (SCC, 1991). Section 14 of the *Criminal Code* states: "No person is entitled to consent to have death inflicted on them, and such consent does not affect the criminal responsibility of any person who inflicts death on the person who gave consent" (GC, 1985a). Considering MAID as an exemption to homicide or to assisted suicide in criminal law, an AR for MAID taken as advance consent to being killed might appear incompatible with the concept of valid consent in criminal law. Thus, allowing ARs for MAID would require consideration of the limits of effective consent in Canadian law and amendment of the *Criminal Code*.

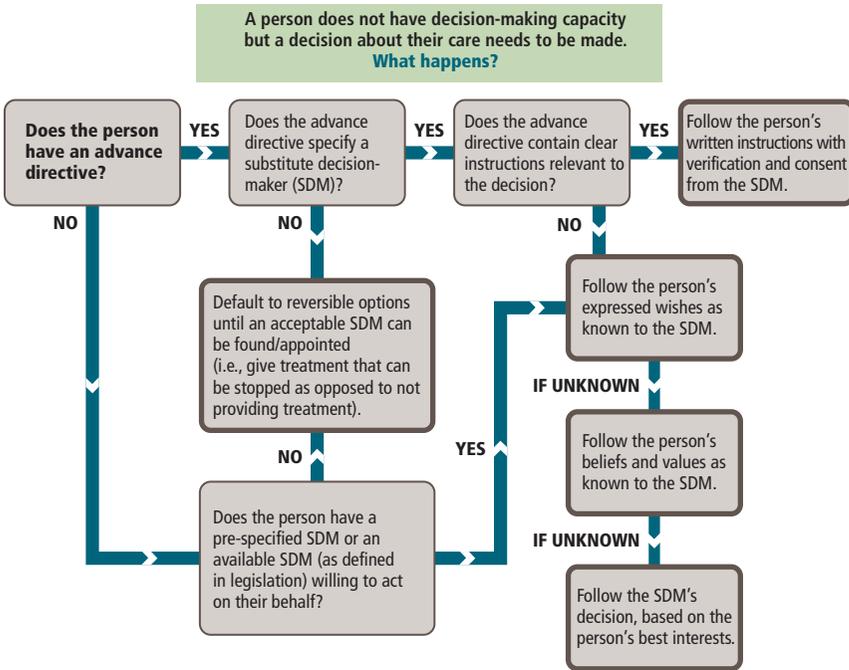
### 3.3.2 Healthcare Decision-Making by People with Capacity-Limiting Conditions

Obtaining informed consent hinges upon a patient's decision-making capacity. Capacity standards tend to increase with the potential impact and irreversibility of decision outcomes; as Kim (2010) notes, “[c]onsequences matter in capacity determination. Specifically, it is widely accepted that the level of abilities required — the threshold for competence — increases as the risk-to-benefit ratio increases.” Concerns or doubts about decision-making capacity complicate the process of informed consent (Waisel *et al.*, 2009; Tait *et al.*, 2014; Mukherjee *et al.*, 2016).

There is a firm, but rebuttable, presumption in Canada that adults have the capacity to make decisions for themselves (subject of course to any laws that prohibit certain behaviours) and that healthcare providers are to respect an adult's decisions (Gilmour, 2017). The legal criteria for capacity, as established by the Supreme Court of Canada in *Starson v. Swayze* (SCC, 2003), are twofold: (i) a person must be able to understand information relevant to the decision at hand, and (ii) appreciate the reasonably foreseeable consequences of the decision's outcome. The assessment of capacity is a judgment made by a healthcare practitioner working with the patient to obtain informed consent. Depending on the type and progression of the disease, and the nature of the treatment decision, a person's capacity may fluctuate over time (CPSO, 2015b). In clinical practice, if a patient lacks decision-making capacity, the healthcare team will work with the patient and their SDM (and family, if available) to obtain consent to treatment that is in keeping with the patient's values, preferences, and wishes.

#### Substitute Decision-Making

In most jurisdictions in Canada, if a person has been found to lack decision-making capacity by their healthcare provider (or by the courts), consent to treatment is sought on their behalf through an SDM (Figure 3.2). If the person, prior to losing capacity, wrote an advance directive following the legislated requirements for their jurisdiction, the relevant instructions contained in the advance directive should be followed; otherwise, the SDM is required to act in accordance with the person's known wishes and values, or, if unknown, in the person's best interests (Figure 3.2). An SDM may be specifically named in an advance directive, or they may be a family member, friend, or court-appointed guardian, depending on circumstances and jurisdiction (e.g., Gov. of PE, 1988; Gov. of NL, 1995; Gov. of ON, 1996; Gov. of YK, 2003b). This is the dominant model of decision-making for people lacking the legally recognized capacity to make decisions for themselves in Canada (Bach & Kerzner, 2010). Figure 3.2 illustrates a generalized schematic of how non-emergency healthcare decisions are made in Canada when a person has lost decision-making capacity.



**Figure 3.2**  
**How Non-Emergency Healthcare Decisions Are Made in Canada when a Person Does Not Have the Ability to Provide Informed Consent**

The figure presents a simplified flow chart of how non-emergency healthcare decisions are made in Canada on behalf of a person who, due to a lack of decision-making capacity, is not able to provide informed consent under the law. This figure was conceptualized by the Working Group, informed by legislation and CMPA (2016a, 2017a).

In practice, conflicts among family members and the care team about a patient’s best interests can complicate the schematic presented in Figure 3.2. Decision-making can also be complicated by ambiguity in the advance directive or uncertainties expressed by the patient to their care team or family members prior to the loss of capacity (Leder *et al.*, 2015). When situations arise that were never referred to or discussed in the advance directive, the clinician and family must extrapolate from the document what the patient would have wanted, which

can be difficult (Perkins, 2007). Family members can contest the directive if they have concerns regarding its validity. In the experience of the Working Group's clinical members, it is not unheard of for a health authority to accede to the wishes of family who threaten to sue or otherwise strongly object to carrying out an advance directive. Evidence on the effectiveness of advance directives, including substitute decision-making, is reviewed in Chapter 5.

### Supported Decision-Making and Co-Decision-Making

*Supported* decision-making, an alternate model to *substitute* decision-making in Canada, extends legal capacity to those who would otherwise be excluded (Stainton, 2015). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasizes that people with disabilities should be provided with support to enable them to make decisions for themselves (UN, 2007). Article 12.3 of the UNCRPD declares: "State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (UN, 2007). Within the supported decision-making model, the decision-maker assists the person rather than imposing their own views and wishes on the other. The philosophical underpinnings of this model align closely with relational autonomy (Bach & Kerzner, 2010), and there has been some discussion of expanding this model to include those living with mental disorders (Davidson *et al.*, 2015).

In 2010, Canada ratified the UNCRPD, but expressed reluctance to abolish all forms of substitute decision-making in favour of a supported decision-making model (as many disability advocates have interpreted the UNCRPD). Some provincial and territorial legislation, however, does incorporate supported decision-making or co-decision-making models (Stainton, 2015). The *Representation Agreement Act* in British Columbia allows for the appointment of a person to help an adult in decision-making (Gov. of BC, 1996b). Yukon, Alberta, and Manitoba also have legislation that recognizes supported decision-making (Gov. of MB, 1993b; Gov. of YK, 2003a; Gov. of AB, 2008a).

The *Adult Guardianship and Co-decision-making Act* in Saskatchewan uses the co-decision-making model, in which the court appoints an individual to assist a person in making decisions (Gov. of SK, 2000). Unlike supported decision-making, co-decision-making does not allow for the person with the capacity-limiting condition to choose their own helper (Bach & Kerzner, 2010).

### ARs for MAID and Substitute Decision-Making

In this report, the Working Group presumes that a person who writes an AR for MAID possesses the legal capacity to make such a request at the time of its drafting. However, if ARs for MAID were decriminalized by removing the requirement for express consent immediately prior to the procedure without the inclusion of specific limits, provinces and territories could allow MAID to be included as an option in current advance directives legislation. Therefore, if not expressly prohibited, ARs for MAID regulated through provincial and territorial legislation could allow an SDM to make a request for MAID on behalf of another person. The role and authority of SDMs in implementing other people's ARs for MAID, should they be permitted in Canada, is uncertain and would require further consideration.

Some provincial and territorial legislation specifies actions that an SDM cannot consent to, such as sterilization that is not medically necessary, or tissue or organ removal for transplantation or research (Table 5.1). No jurisdiction in the world has legislation that allows someone to request an assisted death on behalf of another person without the prior written request of the latter (Gov. of Belgium, 2002; Gov. of the Netherlands, 2002; Gov. of Luxembourg, 2009; Gov. of Colombia, 2015).

Additionally, the eligibility criteria of intolerable suffering as written in current legislation could not apply directly to a request made by an SDM, since intolerable suffering is a judgment made by the person requesting an assisted death (GC, 2016). As defined by the Working Group, an AR for MAID is only valid if it is the express request of the person seeking MAID. Thus, an SDM's request for MAID on behalf of another person, without a documented request made by the latter prior to capacity loss, would not be a valid AR for MAID.

## 3.4 KEY CONCEPTS RELEVANT TO ADVANCE REQUESTS FOR MAID

Making a choice about whether or not to permit some form of ARs for MAID requires policy-makers to take a position on the interplay of autonomy, suffering, and vulnerability. This section outlines the complexities that arise when these concepts are applied to ARs for MAID.

### 3.4.1 Autonomy in End-of-Life Decision-Making

The principle of respecting autonomy is significant in contemporary healthcare ethics. For some, autonomy is solely or predominantly about the right of the individual to make self-regarding decisions — what may be called an *individualistic* account of autonomy (Sherwin, 1998). In this model, once informed about

diagnosis, prognosis, and treatment options, a person has the right to make a decision that accords with their own personal values, desires, or idiosyncrasies, without controlling interference or limitations that prevent meaningful choice (Beauchamp & Childress, 2013). In the individualistic account of autonomy, the emphasis is on the rights to self-determination and non-interference; this perspective is evident in the preamble to Bill C-14, which references the autonomy of a person (GC, 2016). Such an account was also evident in the *Carter* decision, which states that denying the right to request MAID impinges on a person's liberty and security, specifically on their "ability to make decisions concerning their bodily integrity and medical care" (SCC, 2015).

Feminist theory introduced a relational conception of autonomy (Nedelsky, 1989). *Relational* autonomy does not discount an individual person's autonomous decision-making, but rather draws attention to the importance of social relationships when making such decisions (Sherwin, 1998). Our relationships define who we are and what we value in a way that makes true individualism impossible (Sherwin, 1998). Therefore, appropriate inclusion of family and care providers during healthcare decision-making is a way to foster, not detract from, autonomy (Gastmans & De Lepeleire, 2010). It is not then the ability to make a decision that is important; rather "[a]utonomy becomes possible in social interactions through relationships" (Leckey, 2008). Indeed, some argue that MAID is an inherently relational act; it inevitably involves both physician and patient and, as such, falls within the framework of relational, rather than individual autonomy (Gastmans & De Lepeleire, 2010; Deschamps, 2016).

Further, relational autonomy draws our attention not just to the importance of interpersonal relationships, but also to the socio-political contexts in which healthcare is delivered. The Canadian public healthcare system features long-standing inequities in access to healthcare resources, including acute care, home care, long-term care, and palliative care (Banerjee, 2007; Bryant *et al.*, 2010; Sherwin, 2011; Stajduhar, 2011; CHPCA, 2014a). In addition to supporting the autonomy of individuals requesting MAID and the well-being of their families, there is a need to "better understand and deal with the complex socio-political climates in which health care is delivered and in which resources for health are embedded" (Rodney *et al.*, 2013). The importance of recognizing and addressing autonomy lies in how we, as a society, create laws and policies that respect autonomous decision-making and how those laws and policies are put into practice by clinicians, care teams, family, and friends.

### Autonomy and Informed Consent

As noted above, MAID is an exemption in the *Criminal Code* that can only be provided under specific, exceptional circumstances prescribed by law. Medical and nurse practitioners have the authority to evaluate those circumstances, but only at the express request of a patient. The Canadian healthcare system recognizes the rights of patients to make treatment decisions, and healthcare in general has moved towards a patient-centred model of care (see Section 3.1.1). The relationship between patient and healthcare practitioner ideally empowers and respects patient autonomy in the development and implementation of care plans (Constand *et al.*, 2014). Consent is the vehicle that gives legal authority to individual healthcare decisions; the process of obtaining informed consent is seen as demonstrating respect for autonomy (Beauchamp & Childress, 2013).

Although the view that informed consent respects patient autonomy is widespread, it is not universal. For example, Laurie (2002) argues that respecting autonomy is not reducible to obtaining informed consent, and “the conflation of autonomy with consent robs the former of much of its meaning and strips it of much of its ethical credibility.” The requirement to obtain informed consent (or refusal), it has been argued, offers protection against the paternalism that patient-centred healthcare rejects (McLean, 2010). However, there is uncertainty about whether the requirement to obtain informed consent is enough to respect autonomy or to recognize an autonomous decision, in part because autonomy is a contested concept and in part because of the rule-based approach of courts and legislators (McLean, 2010). Additionally, autonomy is not the only value underlying informed consent; informed consent is also a practical way to facilitate and improve the physician-patient relationship (Lemmens, 2015).

A person who lacks capacity under the law lacks the authority to have their current preferences followed. Models of supported decision-making provide people who lack capacity the assistance necessary to retain authority over their choices, though these models are not widely incorporated into Canadian legislation at this time (see Section 3.3.2). Thus, when a person loses the capacity to provide informed consent, their autonomy is embodied in the decisions made by the SDM.

### Considerations of Autonomy in ARs for MAID

A deeply unconscious person may have no self-awareness or awareness of their situation, and may be unable to formulate or express any thoughts or feelings. If such a person had previously written an AR for MAID in the event of their permanent unconsciousness, and there was no reasonable hope they would return to consciousness, then whatever the person had articulated before they permanently lost consciousness would be the last available expression of their

preferences. Thus, there is no potential for conflict or dissonance between their past statement and current preferences (Dworkin, 1993; Menzel & Steinbock, 2013). Similarly, there is no conflict if a person has a neurodegenerative disorder but still has capacity; their current expressed choices are followed regardless of what they may have previously expressed in an AR for MAID.

A moral grey area arises when a person is conscious but has lost some or all decision-making capacity, and when they express emotional responses that counter what is written in their AR for MAID (Menzel & Steinbock, 2013). That is, uncertainty about how to approach an AR for MAID increases if the person who has lost capacity appears indifferent to receiving MAID, expresses a desire to continue living, or physically or verbally resists the MAID procedure. In such situations, it becomes unclear how the autonomy of the past self balances against the real or assumed preferences of the current self.

Dworkin (1993) describes and defends the concept of precedent autonomy, in which a capable person's interests for their future self take precedence over the interests of one's future, decisionally incapacitated self. Dworkin argues that the present, capable self is driven by both experiential interests (doing things that bring pleasure) and critical interests (values and concepts of a personal identity and narrative), whereas the future, incapable self knows only experiential interests (Dworkin, 1993). Thus, the decisionally incapacitated person does not have the full knowledge of their self, and cannot make reasoned, deliberative decisions based on their critical interests. This view centres on an individualistic concept of autonomy, and does not consider relational aspects of decision-making.

Dworkin's concept of precedent autonomy has been criticized for the assumption that the decisionally capable and incapable selves are, in fact, the same "person" despite substantial changes in their psychology (Dresser, 1995). Further, the idea that only capable people can hold critical interests (i.e., personal values) discounts the notion that values may be retained, and therefore changed, irrespective of the entire living narrative (Jaworska, 1999). Moreover, a change of heart can reflect the autonomous decision of a capable person made under novel circumstances, even if that decision appears counter to a person's professed values and beliefs (Jaworska, 2009).

The philosophical debate surrounding autonomy and the ethics of advance directives is ongoing (e.g., Tsinorema, 2015) and may never be resolved. However, Menzel and Steinbock (2013) note that "the more informed, thoughtful, and based in fact an advance directive is, the more moral authority it has." They also state that the strongest case for following an AR for MAID is one in which

the severe and unrelievable suffering of the decisionally incapacitated person is evident; this moral ambiguity about precedent autonomy is less contentious the more obvious the presentation of suffering.

### 3.4.2 The Predicted and Lived Experience of Suffering

Several definitions of suffering share common elements: suffering is distinct from pain or physical distress, is not a symptom of the disease itself, and results from the meaning that a person gives their lived experience (Cassell, 1982; Dees *et al.*, 2009; Gupta *et al.*, 2017). As Gupta *et al.* (2017) note, “suffering is an interpretation of experience, not a sum of symptoms.” An influential definition of suffering comes from Cassell (1982), who defined suffering as “the state of severe distress associated with events that threaten the intactness of the person.” Personal intactness may be threatened by events that change a person’s sense of dignity — their ability to maintain a “unified and meaningful life narrative,” which can include the loss of capacity to participate in relationships or activities from which a person derives a sense of purpose (Pullman, 2002). In Canadian MAID legislation, a grievous and irremediable medical condition is characterized by “enduring physical or psychological suffering that is intolerable to [the person] and that cannot be relieved under conditions that they consider acceptable” (GC, 2016).

A person who no longer has decision-making capacity may no longer be able to articulate the nature or quality of their condition and experience. Thus, the person must rely on others to recognize when the circumstances described as intolerable suffering in their AR for MAID have happened. An AR for MAID would specify some criteria considered by the person who wrote the AR to be intolerable (e.g., being bedridden, not recognizing family members, difficulty breathing, or experiencing pain). These are, however, circumstances of anticipated suffering, which may not reflect the lived experience of the person when they reach those circumstances.

### The Disability Paradox: Underestimating Quality of Life

The primary reasons that patients seek assistance in dying at end of life are the desire for control over their death, fear of losing dignity, and fear of poor quality of life (Fischer *et al.*, 2009; Ganzini *et al.*, 2009; Pestinger *et al.*, 2015; Li *et al.*, 2017). There is a well-established discordance between the *predicted* quality of life of healthy people imagining a future health condition and the *actual* quality of life of people living with said condition (Ubel *et al.*, 2005), a phenomenon termed the *disability paradox* (Albrecht & Devlieger, 1999). The disability paradox suggests that people may tend to overestimate the intolerability of a future health scenario, and may not actually desire MAID should they experience that scenario in the future.

The underestimation of quality of life by able-bodied or healthy people, rather than its overestimation by those living with a disability or chronic illness, drives the disability paradox (Ubel *et al.*, 2005). The disability paradox is pervasive and not limited to healthy people imagining themselves with an illness they have never experienced. For example, former colostomy patients have a higher aversion to living with another colostomy (as measured by the number of remaining months of life they would be willing to trade to avoid having a colostomy, given a hypothetical prognosis of 10 years to live) than current colostomy patients. Despite this apparent aversion, former and current colostomy patients reported similar levels of life satisfaction, quality of life, and health status (Smith *et al.*, 2006). Smith *et al.* (2006) speculate that former patients recalled their colostomy as impacting their quality of life more negatively than current patients because the valuations of former patients were biased by theories about the impact of disability, even though these patients had already experienced living with a colostomy.

While the disability paradox suggests a bias in the accuracy of predictions about future suffering, it does not remove the possibility that a person with a disability may find their situation intolerable. People living with a disability report a high quality of life when they retain control over their bodies, minds, and lives (Albrecht & Devlieger, 1999). Those living with a disability consider themselves to have low quality of life when they have unpredictable and untreatable pain, fatigue, and a loss of control over their bodies and minds (Albrecht & Devlieger, 1999).

### Suffering and Capacity Loss

Suffering is closely related to personhood and occurs when different aspects of a person are threatened, damaged, or lost. Anticipating capacity loss may in and of itself cause suffering; that is, for some people, the knowledge they will lose the control, abilities, and dignity that they currently possess could cause suffering (de Beaufort & van de Vathorst, 2016). Many of those who contributed to Dying with Dignity Canada's Call for Input submission, which supported expansion of the legislation to include ARs for MAID, drew from direct, personal experience of caring for a loved one or client with dementia (Dying with Dignity Canada, 2017a). These carers at times believed their loved one was suffering based on the patient's behaviour; some also expressed a desire to avoid being in that same position one day — dependent, unaware, anxious, and dying. An AR for MAID might reflect someone's sincere desire to avoid intolerable suffering as well as their evaluation of future quality of life based on their observations of another person who lived with dementia.

Some authors distinguish between different types of suffering, notably neurocognitive (suffering associated with the experience of disease symptoms such as pain) and existential (suffering that depends on how the patient believes their illness is affecting their personal identity and the meaningfulness of their life) (Jansen, 2010). People who lack the capacity to consent to healthcare can certainly suffer from either type (or both), unless they are deeply unconscious. To provide care to those who cannot articulate their experiences, healthcare practitioners can and do interpret different behaviours as expressions of suffering. Physicians may rely on physical causes of suffering in an evaluation of a patient's condition, whereas patients may emphasize psychosocial aspects of suffering, such as loss of independence and ability (Pasman *et al.*, 2009). However, clinical standards for judging the suffering of those who lack decision-making capacity can also be biased by “inappropriate value-laden decision-making by healthcare professionals,” such as the presumption of suffering solely because a person has a disability (Tuffrey-Wijne *et al.*, 2018).

Although treatment options such as dignity therapy are emerging to address existential suffering, they are relatively new and their potential has not been fully explored (Chochinov *et al.*, 2005). Dignity therapy “engag[es] patients in a brief, individualized intervention designed to engender a sense of meaning and purpose, thereby reducing suffering in patients nearing death” (Chochinov *et al.*, 2005). A study on different types of end-of-life care (palliative care, client-centred care, and dignity therapy) found that, while dignity therapy did improve some aspects of quality of life, it did not significantly change patients' stated desire for death, will to live, or sense of suffering (Chochinov *et al.*, 2011).

Having an AR for MAID, in and of itself, might relieve suffering in anticipation of capacity loss by providing assurance that one's wishes are known and will be followed at some predetermined time (Section 6.1.2). However, the circumstances written into an AR for MAID could create uncertainty in a third-party decision-maker who bears the burden of deciding when the person is suffering intolerably and would desire MAID (Section 6.1.3).

### 3.4.3 Vulnerability and ARs for MAID

Vulnerability is an inevitability of life. As Fineman (2008) states, “we are beings who live with the ever-present possibility that our needs and circumstances will change.” By forming relationships with other people, we leave ourselves open to betrayal should those relationships deteriorate; as social creatures, we are vulnerable to harm by isolation and a lack of social support (Nussbaum, 1986). *Inherent vulnerabilities* are features of our conditions that necessitate dependencies (MacKenzie *et al.*, 2014). A person who lacks decision-making capacity is inherently vulnerable in that they are reliant on caregivers, clinicians,

and those who make decisions on their behalf to provide them with the best possible outcomes. However, the family members and caregivers of those lacking decision-making capacity are also vulnerable given the complex relationships of support and interdependency of which they are a part (Harding, 2017). Vulnerable people must be protected from coercion and subtle influence in the drafting and application of an AR for MAID, particularly given that the AR for MAID would be implemented only after a patient has lost decision-making capacity.

Without having known the person prior to their capacity loss, it may be difficult or impossible to know the circumstances under which a person wrote their AR for MAID and difficult or impossible, therefore, to assess the voluntariness of their written request and the extent to which they were informed of their condition (van Delden, 2004). People may be most vulnerable to harm in cases of severe capacity loss, as they have lost the ability to express concerns, articulate grievances, or advocate for themselves.

*Situational vulnerability* refers to vulnerability that is context-specific (MacKenzie *et al.*, 2014). For example, geographic isolation and financial constraints, when they limit access to healthcare resources, can render people vulnerable to a myriad of health problems. People who only have access to poorly organized or even dangerous health services are vulnerable to disease, injury, or exacerbation of existing health conditions (PHAC, 2018). A recent investigation found that the majority of long-term care (LTC) facilities with the highest abuse rates were in rural communities (Osman, 2018). Three sources of situational vulnerability are particularly relevant for people who experience capacity loss and those who care for them: stigma, caregiver stress and burden, and inadequate community and residential LTC services.

### Stigma

A growing body of research suggests that, among people with dementia, stigma promotes social exclusion and a reluctance to seek help (Benbow & Jolley, 2012; Herrmann *et al.*, 2018). Unfortunately, stigmatizing attitudes towards people with dementia are found among healthcare practitioners and the public, negatively affecting those with the condition (Herrmann *et al.*, 2018). People with dementia note changes in their relationships and treatment by others, including those in the medical profession, which impairs patients' well-being (de Boer *et al.*, 2007). Stigma distorts services at all levels, from decisions about whether to seek help, through the design and provision of health services, to political discussions around priorities and resource allocation (Benbow & Jolley, 2012).

While people with dementia have both positive and negative care experiences, satisfaction and quality of life are positively associated with feeling useful and engaging in meaningful activities (de Boer *et al.*, 2007). Primary concerns of people with dementia centre on loss of ability, memory, and skills, as well as sense of self and self-esteem (de Boer *et al.*, 2007). The Canadian Dementia Priority Setting Partnership (comprising people with dementia, their care partners, and frontline care providers) used methods approved by the James Lind Alliance to identify and prioritize their 10 top research questions (Bethell *et al.*, 2018). The number one question they wish to have answered involves stigma: How does stigma impact people and what are effective ways of reducing it?

### Caregiver Stress and Burden

People who develop progressive neurological diseases that affect their capacity often become dependent on family members and occasionally friends to provide the care they require. As Alzheimer's disease progresses, for example, people will eventually require 24-hour care at home or in residential LTC facilities (Alzheimer's Association, n.d.). Family caregivers take on enormous responsibility to ensure the safety, health, personal care, and quality of daily life of their family members. Caregivers report being most challenged by verbally and physically aggressive behaviour, delusions, irritability, and other behaviours that affect their relationship with the patient; these behaviours are associated with higher levels of stress and depression in caregivers (Cheng, 2017). Needing assistance in hygiene and toileting requires significant time commitments by caregivers and contributes to caregiver burden (Cheng, 2017).

Caregiver stress and burden can be detrimental to the caregiving relationship, creating situations where both the person with dementia and their caregiver are vulnerable to harm. For example, verbally and physically aggressive behaviours can injure the physical and mental well-being of caregivers (Cheng, 2017). At the same time, the use of sedatives or antipsychotics can be detrimental to the person with dementia. Adequate support for caregivers can create the opportunity to address the triggers for problematic behaviour and enhance the experiences of both caregiver and patient (Harding, 2017).

### Availability of Care Services

The availability of home care services (e.g., nursing, personal care, homemaking, rehabilitation) and residential LTC services varies considerably both within and among the provinces and territories (Banerjee, 2007; Johnson *et al.*, 2017). Availability may vary due to geography and budget priorities, and because

neither home nor residential LTC service is subject to the *Canada Health Act* (Banerjee, 2007; Johnson *et al.*, 2017). People in rural or remote areas have less choice of nursing homes within reasonable distance to their families and less access to the same range and intensity of home-care services than urban dwellers (e.g., Lord, 2017). Nunavut presents an extreme example of this discrepancy; as of April 2018, Nunavut had a population of 38,456, located in 25 communities (Gov. of NU, 2018a, 2018b). A 2015 report on continuing care in Nunavut noted that only five of these communities had an LTC facility and home care was not available on weekends or evenings (LAN, 2015). In contrast, Ontario, with a population of approximately 14.4 million in April 2018 (Gov. of ON, 2018b) and half the geographic size of Nunavut, had 627 nursing homes in 2015 (OLTCA, 2016). However, depending on location and need, it is possible to find people with and without access to the services they require in both Nunavut and Ontario.

Most jurisdictions report a shortage of LTC beds and long wait lists (Conference Board of Canada, 2017; Tutton, 2017). This leaves patients and caregivers dependent on home care services that may be inadequate (Tutton, 2017). If people who are at end of life move across provincial or territorial borders to be closer to family, they will not qualify for home care services, drugs, or hospice care until they have met the residency requirement in their new province or territory (Picard, 2018). Having appropriate levels of home-care services can keep people with compromised health out of residential care and in their family home. People with a prognosis that includes future loss of capacity anticipate vulnerability due to factors over which they do not have direct control, including societal stigma, caregiver stress, and availability of adequate home and residential care. These factors could influence deliberations about MAID and ARs for MAID.

### 3.5 CHAPTER SUMMARY

People in Canada have the right to choose (or refuse) healthcare that is medically indicated and within the standard of care. Such rights and practices extend to future healthcare using ACP and advance directives. Extending these rights to MAID through an AR for MAID, however, would raise important considerations regarding what consent means in clinical and legal contexts, as it would require removing a safeguard — that of providing express consent immediately prior to the MAID procedure. ARs for MAID also give rise to diverse perspectives on autonomy in decision-making, suffering, and vulnerability. Full reconciliation of such perspectives may not be possible, but making a policy decision on allowing

or prohibiting ARs for MAID requires taking a position that addresses the interplay of these key concepts, informed by relevant evidence. For example, even with the use of advance directives for healthcare, practitioners in Canada seek the confirmation of consent from an SDM prior to providing treatment (emergencies notwithstanding). The role and authority of an SDM in the carrying out of an AR for MAID would involve complex factors that may not be apparent at face value; these are explored further using patient vignettes in Chapter 4.

# 4

## **Issues and Uncertainties Surrounding Advance Requests for MAID: Three Scenarios**

- **Trajectories of Diseases or Conditions that Affect Decision-Making Capacity**
- **Scenario 1: Advance Requests Made When Patient Is Eligible for MAID**
- **Scenario 2: Advance Requests Made After Diagnosis but Before MAID Eligibility**
- **Scenario 3: Advance Requests Made Before any Diagnosis**
- **Summary of Uncertainties in Administering Advance Requests for MAID**
- **Chapter Summary**

## 4 Issues and Uncertainties Surrounding Advance Requests for MAID: Three Scenarios

### Key Findings

A key driver for creating an AR for MAID is fear of losing decision-making capacity. A number of conditions can lead to loss of capacity, including neurodegenerative diseases and brain injuries.

A patient may wish to create an AR for MAID if they are already eligible for MAID but fear losing the capacity to provide consent before the procedure, if they have a disease that is certain to cause capacity loss, or if they are healthy but fear a sudden event may remove their capacity and leave them suffering intolerably.

The possibility of permitting ARs for MAID raises broad clinical and legal questions related to legislation and implementation. A key question is how to deal with intolerable suffering in the context of ARs for MAID when a patient can no longer communicate their level of suffering at the time that MAID is to be provided.

Other uncertainties involved in implementing ARs for MAID could arise at the individual level and would be influenced by (i) the patient's physical and psychological state; (ii) the clarity with which the patient communicates their wishes; and (iii) the strength of the patient's relationships with their care team and loved ones.

The timing of an AR for MAID in relation to its implementation could influence the complexity of an individual case. ARs prepared shortly before MAID is to be provided (e.g., when a patient already meets eligibility requirements) would involve much less uncertainty than requests prepared months or years before implementation.

This chapter explores the circumstances under which someone might seek an AR for MAID and the types of issues or considerations that could arise if ARs for MAID were permitted. It does so by way of patient vignettes that fit under one of the following three scenarios:

1. a patient writes an AR when already eligible for MAID to mitigate any risk of losing capacity (and therefore becoming ineligible) while waiting to receive it;
2. a patient prepares an AR after diagnosis with a serious condition but prior to meeting all eligibility criteria; or
3. a person writes an AR prior to any diagnosis.

These scenarios identify a number of issues or considerations, many of which are related to the fact that ARs for MAID would require third parties to make a life-or-death decision on behalf of someone else when they can no longer confirm this person's wishes. This could give rise to uncertainty about understanding the patient's physical and/or emotional state, interpreting the AR for MAID and applying it to the patient's circumstances, and determining the strength and persistence of the patient's wishes. Uncertainty may be greater in cases where the patient's healthcare team and family are not familiar with their values, wishes, and circumstances, and must interpret the AR for MAID without this knowledge. The scenarios explore these uncertainties and the key questions that may arise when implementation of a given AR for MAID is being considered. The chapter begins with a brief overview of the types of capacity-limiting diseases and conditions that may prompt someone to draft an AR for MAID.

#### **4.1 TRAJECTORIES OF DISEASES OR CONDITIONS THAT AFFECT DECISION-MAKING CAPACITY**

ARs for MAID respond to people's concerns about potentially losing the ability to make end-of-life decisions should they develop a disease or condition that could impede decision-making capacity (Table 4.1). While capacity loss may happen immediately following an accident or stroke, a number of degenerative disorders may not result in capacity loss until months or years after diagnosis.

Dementia, the most common neurocognitive disorder in Canada, may be caused by a number of disease conditions or injuries to the brain, including Alzheimer's, Huntington's, Parkinson's, or Lewy body disease; traumatic brain injury; hypoxia related to heart failure; and various endocrine, nutritional, immune, and metabolic conditions (APA, 2013). Under current law in Canada, people with a neurocognitive disorder are not explicitly ineligible for MAID; they can still qualify provided they have capacity to consent to the procedure at the time it is carried out and meet all other eligibility criteria (e.g., death is reasonably foreseeable). A patient's particular condition may not only inform their decision to seek an AR for MAID, it may also introduce novel complexities for the implementation of this request. For example, implementing the AR of a patient with dementia who alternates between moments of contentment and periods of anxiety, anger, and sadness might be more complex than implementing the AR of a patient with end-stage cancer who has a stroke that results in irreversible unconsciousness.

Table 4.1

## Trajectories of Diseases or Conditions that Lead to Loss of Capacity

	Description	Disease Progression	Impact on Decisional Capacity
Alzheimer's Disease	<ul style="list-style-type: none"> <li>• Functional impairment</li> <li>• Wide variety of cognitive changes (short-term memory loss) including behavioural and personality</li> <li>• Alzheimer's comprises about 80% of all dementias</li> </ul>	<ul style="list-style-type: none"> <li>• Variable onset: can be rapid (within a year) or slow (within decades), depending on patient-specific factors</li> <li>• Typical life expectancy is 8 to 10 years</li> <li>• Eventually bedridden</li> <li>• Often die from infection, starvation</li> </ul>	<ul style="list-style-type: none"> <li>• Depends on stage of disease — people may be fully capable in early stages with gradual loss of decisional capacity as disease progresses</li> <li>• Slow loss of ability to complete tasks</li> <li>• Eventually unable to care for self or make simple decisions</li> <li>• May have anxiety, fear, or anger; hallucinations may occur in more advanced stage</li> </ul>
Huntington's Disease	<ul style="list-style-type: none"> <li>• Starts with jerky, uncontrolled, random movements of arms, legs, head, and face; evolves into writhing movements and rigidity, grimacing of face</li> </ul>	<ul style="list-style-type: none"> <li>• Varies across individuals, but typically a long period of decline up to 15 to 20 years</li> <li>• Unable to speak or move and have great difficulty eating in advanced stage of disease</li> </ul>	<ul style="list-style-type: none"> <li>• Mood changes and irritability early; later, apathy and dementia</li> <li>• Loss of decisional capacity in advanced stage</li> </ul>
Parkinson's Disease	<ul style="list-style-type: none"> <li>• Early symptoms include shaking, slow movement, rigidity, and problems walking</li> </ul>	<ul style="list-style-type: none"> <li>• Around 10 years</li> <li>• Patients usually become bedridden in advanced stage and are unable to care for themselves</li> </ul>	<ul style="list-style-type: none"> <li>• Some cognitive and behavioural changes are possible, such as anxiety and/or depression</li> <li>• Dementia is common in advanced stage of disease</li> </ul>

*continued on next page*

	Description	Disease Progression	Impact on Decisional Capacity
Stroke	<ul style="list-style-type: none"> <li>Loss of motor/sensory on one side of the body</li> <li>Can be limited to small parts of the brain and affect speech and cognition</li> </ul>	<ul style="list-style-type: none"> <li>Generally once it occurs it doesn't worsen (if caught early and given treatment); at risk for further strokes</li> <li>Patients can live many years with significant impairment</li> </ul>	<ul style="list-style-type: none"> <li>Depends on the patient and area of brain affected</li> </ul>
Brain Cancer	<ul style="list-style-type: none"> <li>Starts with headaches (associated with nausea) and non-specific neurological symptoms</li> <li>May change motor and sensory function, personality, and cognition</li> </ul>	<ul style="list-style-type: none"> <li>Variable: dependent upon whether surgery and radiation are possible as well as extent at diagnosis; months to years</li> <li>Headache and seizures may be severe</li> <li>Death from increased intracranial pressure or secondary illness (e.g., pneumonia)</li> </ul>	<ul style="list-style-type: none"> <li>Depends on the patient and area of brain affected</li> <li>May lose all function (cognitive, motor) and be in a vegetative state near death</li> </ul>

Conceptualized by the Working Group, informed by Sontheimer (2015)

## 4.2 SCENARIO 1: ADVANCE REQUESTS MADE WHEN PATIENT IS ELIGIBLE FOR MAID

The first scenario considers the use of ARs for MAID when patients have met the eligibility criteria for MAID but may fear losing capacity to consent prior to the procedure. This scenario could occur as a result of two safeguards in Canadian law: one is the requirement for 10 clear days<sup>5</sup> to pass between the date that a MAID request was signed and witnessed, and the date that MAID is provided (GC, 2016). The other is the requirement for express consent from the patient immediately before MAID is provided, thereby giving the person an opportunity to withdraw their request (GC, 2016). This scenario is considered in Box 4.1.

<sup>5</sup> In calculating the number of “clear days,” the days on which the events happen (i.e., the signing of a request and the provision of MAID) are excluded (GC, 1985b).

**Box 4.1****AR for MAID When Already Eligible: Mo**

Mo is an 86-year-old man who requested MAID and was found eligible to receive it. Mo has suffered several strokes in the past year. He is concerned that, if he were to have another stroke before the 10-day waiting period was over, he might lose capacity to provide express consent to MAID. Although the law permits the 10-day waiting period to be shortened if loss of capacity is imminent, Mo's physician believes another stroke is possible but not imminent. Moreover, Mo has also indicated that he would like to spend as much time as possible with his wife, who supports him in his request for MAID. Mo decides to make an AR for MAID in case he loses capacity during the 10-day waiting period. On the eighth day of the waiting period, Mo has another stroke and lapses into a coma.

The case of Mo is relatively straightforward, though it does give rise to one key consideration: what if Mo's stroke had left him in a state in which his cognitive abilities remained, but he was unable to communicate in any way? And what if he had changed his mind about MAID, but was unable to voice this change of heart? For this issue to materialize, it would be necessary for two separate and unlikely events to converge.

First, Mo would need to change his mind, despite already making a request for MAID and already being assessed as eligible. Preferences are frequently context-dependent and as such, may change as a patient's experience of illness and decline alters the context in which decisions are made (Ditto & Hawkins, 2005). Mo's material circumstances are unlikely to change significantly during the short timeframe between writing the request and having it carried out, but it is still possible that he could change his mind. Another reason why a change of heart is unlikely for Mo is that he is already in an advanced state of irreversible decline (a necessary criterion for MAID eligibility), and is therefore unlikely to regain capacity and alter his wishes.

Second, Mo's abilities would need to be affected in such a way that he retained enough mental capacity to change his mind, but was unable to communicate that he no longer desired MAID. This could occur in rare cases, such as that of locked-in syndrome, where patients remain conscious, often with fully functioning minds, yet may only be able to move their eyes and blink (Laureys

*et al.*, 2005). It could also occur in patients with post-stroke aphasia, which affects the ability to use and/or understand words (Fonseca *et al.*, 2017). Depending on the type of stroke and the time between stroke onset and hospital arrival, aphasia frequencies following stroke range from 9 to 62% (Flowers *et al.*, 2016).

#### **4.2.1 Is an AR for MAID Required Under this Scenario?**

One could ask why an AR for MAID would be required in a situation such as Mo's, in which the AR protects the patient from disqualification should capacity loss occur during the 10-day waiting period. Why could the waiting period not be shortened or eliminated altogether where appropriate? The 10-day waiting period is likely meant to ensure that a patient's decision to seek MAID is stable and well-considered (Downie & Chandler, 2018). Furthermore, Canada's MAID legislation already allows the 10-day waiting period to be shortened if "[the two MAID assessors] are both of the opinion that the person's death, or the loss of their capacity to provide informed consent, is imminent" (GC, 2016). What if neither death nor capacity loss appears to be imminent, but the patient is in great discomfort and would prefer to receive pain medication that puts them at risk of permanently losing the capacity to consent to MAID? As Downie and Chandler (2018) note, Canada's MAID law does not specify whether the imminent loss of capacity must be a natural progression of the decline, or whether it includes capacity loss due to treatment. If the latter interpretation is used, a patient whose suffering could only be relieved by a treatment that might cause permanent capacity loss (e.g., sedation or pain medication) would not have to wait the full 10 days to access MAID.

What if the patient does not want the waiting period to be shortened — or even wishes to schedule their MAID procedure outside the 10-day period to coincide with a family visit — but still wishes to receive pain medication that could cause permanent capacity loss while waiting for MAID? Because of the requirement in Canada's current MAID legislation for patients to reiterate their consent immediately prior to receiving MAID, some patients in Canada have refused pain medication to ensure they retain the capacity to provide this consent (UHN, 2017). Allowing advance consent in the form of an AR for MAID following the approval process would prevent such circumstances.

The Working Group's clinical members note that, in their experience, optimal management of symptoms through pain medication does not necessarily reduce cognition; however, patients may have other clinical issues that could act alone or in concert with medication to diminish their cognitive capacity.

### 4.3 SCENARIO 2: ADVANCE REQUESTS MADE AFTER DIAGNOSIS BUT BEFORE MAID ELIGIBILITY

Patients who are living with an illness but who do not yet qualify for MAID might wish to make an AR for MAID because they fear a potential event could compromise their capacity to provide consent (e.g., stroke, accident) or because they have a condition that is certain to cause capacity loss (e.g., neurodegenerative disease). In Scenario 2, some cases would be more difficult than others for third-party decision-makers. For example, if a patient's death is not imminent, or if a patient is still conscious and able to express emotions (even through inarticulate expressions of fear and distress), it might be more ethically challenging for others to decide when (or whether) the patient's AR for MAID should be followed. In contrast, if a patient is expected to die very soon, or is irreversibly unconscious, third parties might be more comfortable following the AR for MAID. To cover both these situations, the Working Group uses two patient vignettes (Boxes 4.2 and 4.3).

#### **Box 4.2**

#### **Advance Request for MAID After Diagnosis but Before MAID Eligibility: Luc**

Luc was diagnosed with an advanced cancer and is receiving palliative care at home. At present, he is not suffering intolerably; his pain and discomfort are well managed. He is preparing memory books for his grandchildren, connecting with friends when he has the energy, and spending time with his wife and children. Recently, he has needed increasing doses of pain medication. Luc has made clear to his family doctor, palliative care physician, and family on numerous occasions that, if his suffering becomes intolerable, he would like MAID. He wants his death to be a peaceful event surrounded by loved ones and he does not want his family to watch him suffer. He has repeatedly stated: "When I'm ready to go, I just want to go." In case he loses capacity, Luc wants his family to have a good understanding of his wishes, which he hopes will help them make decisions on his behalf. He drafts an AR for MAID that outlines the circumstances under which he would like to receive MAID and shares this with his physicians and family. Shortly after Luc indicates that his pain is worsening and he would like to submit his MAID request very soon, he has a stroke that leaves him with severe cognitive impairment.

**Box 4.3****Advance Request for MAID After Diagnosis but Before MAID Eligibility: Vi**

Vi is an 89-year-old woman with a slowly progressing dementia that was diagnosed when she was aged 78. Shortly after her diagnosis, she drafted an AR for MAID with her family doctor, stating that she would like her request fulfilled when she appears generally unhappy most of the time, no longer recognizes any of her friends and family, and is no longer able to perform basic tasks such as bathing and dressing herself. She made it clear that her dignity is very important to her, and that she does not wish to exist if she can no longer look after herself or have meaningful interactions with her loved ones. While she was still capable, Vi told her family doctor more than once that she wanted to die under these circumstances and updated her written request. She was not comfortable, however, discussing the details of her AR for MAID with her children.

Eleven years later, Vi can no longer express herself clearly. Sometimes she appears cheerful and content; other times she seems agitated or sad. Vi's two children feel that she is suffering, but are having trouble determining whether her current situation meets the conditions of her AR for MAID. Her son is concerned about the MAID procedure, wondering whether his mother might become scared and confused. Vi recently moved into an LTC home where she sees a rotating group of physicians. She had a long-standing, open relationship with her family doctor who had detailed knowledge of her motivations for MAID. Unfortunately, he retired a year ago and is no longer available to advise her new care team.

Below, the Working Group considers some complexities that could arise for Luc, Vi, their families, and their healthcare teams. Most of the issues raised are case-specific (i.e., they would influence the complexity of an individual AR for MAID). This section also examines broader legal and clinical questions about dealing with the requirement for intolerable suffering in the context of ARs for MAID.

**4.3.1 Was the Patient's Advance Consent for MAID Well-Informed?**

To provide informed consent, patients must be given information about their diagnosis, treatment options, and prognosis with and without treatment. They must have the capacity to understand and use this information to make a voluntary healthcare decision, and they must appreciate the consequences of

making a decision. Compared with someone whose wish for MAID was driven by a disease that caused capacity loss, Luc's capacity was less likely to be an issue at the time he drafted his AR. He appeared to be well aware of his end-of-life options. However, it is possible that an undiagnosed depression may have affected Luc's capacity when he wrote his AR. Depression, particularly if severe, has been shown to impair decision-making capacity by affecting one's ability to appreciate consequences (Hindmarch *et al.*, 2013). Furthermore, when someone is making a decision about a future healthcare intervention, a special challenge arises in assessing whether they understand and appreciate the difficulties of predicting their own future suffering.

Vi drafted her AR for MAID shortly after her dementia diagnosis when she still had the cognitive capacity to provide informed consent. She thoroughly discussed her situation with her family doctor, who was satisfied that she understood everything and still wished to create her AR. However, Miller *et al.* (2018) caution against the presumption that patients in the early stages of dementia have the capacity to make an AR for MAID.

Compared with Mo and Luc, Vi had a considerable amount of time to think about her illness and preferences about MAID. Other patients contemplating an AR for MAID would have even more time. For example, in the case of a neurodegenerative disease that is detectable before the point of onset (e.g., Huntington's disease), patients who choose to undergo testing may have many years to reflect on their disease (Sontheimer, 2015).

Informed consent is a process through which information is shared and queried. Thus, assessing the adequacy of informed consent from a written document is challenging if the document was written in the absence of physicians or family members (van Delden, 2004). What if Luc and Vi had made conscious decisions to draft their ARs alone, without discussing their wishes with anyone? Or, what if they wanted support from family or community members, but it was not available to them? Unless their ARs were extremely clear, it might be difficult for others to interpret them without prior discussion of their contents.

Vi had a good relationship with her family doctor, but he is no longer involved in her healthcare. Her current healthcare team is new and did not know her prior to capacity loss, which raises an additional concern related to informed consent. Her new team is not comfortable assessing whether Vi made an informed choice in creating an AR for MAID.

### 4.3.2 Does the Patient's Healthcare Team Have Sufficiently Detailed Instructions for Fulfilling the Advance Request?

Compared with Luc, Vi's situation arguably requires an AR for MAID with more specific, clear instructions stating what she considers to be intolerable suffering and when MAID should be performed. For Luc, while clear instructions are still important, they are less critical since he had decisional capacity until the advanced stage of his disease, and was therefore able to reiterate his request at that time. Vi's family doctor was clear about the circumstances under which she desired MAID and her reasons for wanting it. Vi and her doctor discussed the elements of her life that were most important to her and the losses that would reduce her quality of life to the point of intolerable suffering. She did not thoroughly discuss her request with her children, however, and her doctor is no longer available. Vi listed "general unhappiness" as one of her conditions for MAID in her request, but her children are not sure whether she fulfils this condition yet, since she still has periods of contentment. Menzel and Steinbock (2013) note that dealing with the advance request for euthanasia of a "happily demented" patient would represent a great challenge. Although Vi would not be classified as happily demented, as she is often anxious and sad, her children are struggling over whether her current condition is what she had envisioned when she drafted her AR for MAID.

Even if patients have been diagnosed with a specific condition, it can be difficult for them to predict the various circumstances in which they might find themselves, how they will feel about each one, and how others should interpret their behaviour. Vi included the inability to recognize family members as one of the conditions in her AR for MAID. Van Delden (2004) asks when exactly one can say that this loss of recognition has occurred: is it "when [she] fails to recall their names, or when [her] behaviour no longer shows that [she] is familiar with them?" Although more carefully worded ARs can help, they can also make a document lose its sensitivity; that is, the document may not adequately capture the potential situations in which MAID is desired (van Delden, 2004).

In discussing advance directives for healthcare, Shaw (2012) notes the same issues (inability to predict future events and feelings; under- and over-specificity of directives) and suggests that directives must strike a balance in terms of specificity. Providing reasons for advance decisions could help physicians and family members resolve applicability issues they might encounter when dealing with someone who has lost capacity. For example, if patients with dementia considered the possibility that they might become happy as their dementia progresses, and that this would be an acceptable situation for them, they

could state that in their AR for MAID (Shaw, 2012). In providing this detail, they would be letting their caregivers know that their motivation for MAID is not that they view dementia *in general* as a situation of intolerable suffering, but that they are trying to protect their future self from feeling sad, lonely, confused, and scared. An interview study of 29 people with illnesses who had completed advance directives supported this view (van Wijmen *et al.*, 2014). Several interviewees offered vivid examples of experiences they hoped to avoid at end of life, and these examples provided important insight into the reasons for their advance directives. Even if patients discuss their motivations with others, a question remains about what objective criteria could be used to determine when exactly a patient meets the conditions in their AR for MAID. How might family members be assisted as they cope with the burden of this determination?

#### **4.3.3 Are the Patient's Current Preferences Reflected in Their AR for MAID?**

Preference stability is another issue in cases where patients can no longer communicate their wishes. Changes in preferences could be dealt with by frequent renewal of an advance directive. Based on data collected from 2002 to 2004, Vezzoni (2005) notes that approximately half of nursing home and family doctors in the Netherlands advised patients to renew their directives. While some recommended renewal if they felt it was needed, only 32% of nursing home doctors and 38% of family doctors advised regular renewal after a fixed period, regardless of the patient's specific circumstances (Vezzoni, 2005). With any type of instructional directive, even with frequent renewal, physicians and family members might still question whether they are following the patient's wishes after clear communication is no longer possible. Patients who are cognitively impaired can still have subjective experiences, wishes, and preferences that might differ substantially from the preferences they expressed in an AED while decisionally capable (de Boer *et al.*, 2010b). What if they have changed their mind about wanting MAID, but can no longer make themselves understood?

In Vi's case, there are no strong indications that her MAID preferences have changed, despite the change in her circumstances. Although she can no longer express herself, her behaviour still suggests that she is unhappy most of the time, and her AR indicates that this state of unhappiness constitutes intolerable suffering for her. What if, despite her unhappiness, she did not express a desire for MAID, or she specifically expressed a desire to live?

#### 4.3.4 Can Third-Party Decision-Makers Interpret the Current Wishes of a Person Who Lacks Capacity?

One of the central features of ARs for MAID — the fact that the instructions they contain would not become relevant until a person has lost capacity — would force third-party decision-makers to play a major role in their implementation. As demonstrated in the above scenarios, it would be beneficial for patients and family members to have an ongoing dialogue about the motivations behind the conditions set out in an AR for MAID. Luc had this dialogue with his family. Vi repeatedly discussed MAID with her family doctor and was diligent in updating her AR. Even as Vi's dementia progressed, she indicated that she was holding steadfast in her wish for MAID. She was not quite as comfortable discussing MAID with her children, however, and they are now having trouble interpreting her current feelings about MAID; they are unclear about precisely when her request should be carried out to ensure that her wishes are followed as closely as possible.

Interviews with patients who wrote advance directives revealed that some adjusted their views about the level of pain or disability they were willing to tolerate (van Wijmen *et al.*, 2014). These patients did not have illnesses that involved progressive cognitive decline, however, and were simply able to revise their directives. For caregivers of patients with a neurodegenerative disease, it might be difficult to know how to proceed, particularly if their loved one's wishes are not entirely clear. This situation is exemplified by the Dutch euthanasia case 2016-85 (also discussed in Section 4.3.7) involving a woman with Alzheimer's disease who stated in an AED that she wished to undergo voluntary euthanasia when she needed to be moved into an institution for elderly patients with dementia (RTE, 2017d). In the last year of her life, she became decisionally incapacitated and began making conflicting statements about death. When her family doctor described the euthanasia process, she said that she thought this was going too far, but when the doctor mentioned placement in a nursing home, her response was "all right, maybe then" (RTE, 2017d). Yet, after she was moved to the nursing home, when dying was discussed, she again said "not now though, it's not that bad yet" (RTE, 2017d). These types of situations place considerable pressure on family members and care teams.

### 4.3.5 How Should Intolerable Suffering Be Dealt with in the Context of ARs for MAID?

Under Canada's current legislation, patients can initiate a MAID request if *they* decide that their condition is causing them “enduring physical or psychological suffering that is intolerable to them and cannot be relieved under conditions that they consider acceptable” (GC, 2016). Although healthcare practitioners need to confirm that the intolerable suffering criterion has been met, the legislation does not require an independent judgment of the patient's level of suffering by a third party (GC, 2016). If the requirement for a declaration of intolerable suffering immediately prior to the provision of MAID were to remain in any legislation that allowed ARs for MAID, who would this declaration come from? At this point, the patient might be unable to communicate their level of suffering. What level of interpretation would be required of a third party? Would the legislation need to state that a patient's AR for MAID would only be followed when they met the conditions set out in their request *and* when they were judged by others to be suffering?

Third party determination of intolerable suffering raises several issues. First, it is difficult to evaluate suffering in others since it is a personal, subjective experience (Section 3.4.2). As Cassell (1982) states, “[t]he only way to learn [...] whether suffering is present, is to ask the sufferer.” Second, allowing third parties to make this determination would create a situation in which ARs for MAID could be disregarded at the discretion of others; this would contradict the very purpose of an AR — to create a document with legal force that ensures respect for one's wishes (Menzel & Steinbock, 2013). Third, not only do people have different views on the circumstances that constitute intolerable suffering, they also have different reasons for wanting to prepare an AR for MAID, which might *not* be based entirely on avoidance of personal suffering. According to Menzel (2018), avoiding suffering is not the primary reason many people would want an AED for dementia, but rather:

One may simply want one's life not to be capped off by years of severe dementia, with their absence of engagement and communication, their burden on devoted loved ones who will still come even when your meagre reaction will provide them little if any gratification or their distinct potential to exhaust resources that one really does care about leaving to beloved family, friends and causes.

The issue of interpreting the intolerability of someone else's suffering is explored further in Section 6.1.3.

### 4.3.6 Are People Comfortable Making the Choice to End the Life of Someone Who Has Lost Capacity?

Luc is supported by friends, family, and palliative care in his final months while Vi relies heavily on her two children. Luc's close family members have some insight into his feelings about MAID and are thus actively involved in helping to decide when MAID should be provided; Vi's children have more limited insight. When it comes to respecting ARs for MAID, family members could provide confirmatory evidence of a patient's values and preferences based on their intimate knowledge of the patient.

Not all patients have this level of support. They might live alone in a nursing home with no family or community assistance and poor access to palliative care. It may be hard to determine whether such a patient's AR for MAID is driven by loneliness and lack of supportive healthcare services instead of a genuine wish for MAID. Under these circumstances, a healthcare practitioner might not feel comfortable providing MAID based solely on a written request that could not be substantiated or further explained by someone close to the patient.

Luc and Vi have families who support their desire for MAID. However, what if Luc's wife (whom he chose as his SDM) is still dealing with the shock of his stroke, is not ready for her husband to receive MAID, and instead requests palliative sedation, which Luc specifically stated he did not want? Should Luc's physician keep him comfortable with palliative sedation while his wife comes to terms with the situation? In some cases in the Netherlands, relatives found it difficult to follow through with an AED, and instead asked physicians to forego life-sustaining treatment (Rurup *et al.*, 2005; de Boer *et al.*, 2011). Reasons for the reluctance of family members are explored in Section 5.5.1.

Vi had a close relationship with her family doctor and, if he was still treating her, he might have been open to fulfilling her AR for MAID, or helping her family and new healthcare team make a decision about when to provide it. Physicians in the Netherlands (the only jurisdiction where euthanasia has been performed and reported in a situation such as Vi's) rarely implement AEDs under circumstances of advanced dementia (de Boer *et al.*, 2010a, 2011). Their hesitancy to follow AEDs in decisionally incapacitated patients is explored in detail in Section 5.5.2.

### 4.3.7 What if the Patient Resists During the MAID Procedure?

A patient's behaviour at the time of the procedure could create another source of uncertainty in dealing with ARs for MAID (Widdershoven & Berghmans, 2001; Gastmans & De Lepeleire, 2010). Vi's son is worried that she might become

scared and confused, which then raises the question of how her behaviour should be interpreted. If a patient resists during the procedure, would this indicate dissent or an unrelated manifestation of their illness? Premedication with a sedative is a practice endorsed by the Dutch *Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide*, but these guidelines assume that the patient has capacity and wants a sedative because they “[do] not wish to be aware of the moment of coma induction” (KNMG & KNMP, 2012).

Physicians in the Netherlands have expressed their concern about “secretly” euthanizing someone with advanced dementia by administering a sedative without their knowledge (Chabot, 2017; nietstiekembijdemencie.nl, 2017). This concern stems, in part, from one particularly controversial Dutch euthanasia case (2016-85) involving the surreptitious administration of a sedative in a decisionally incapacitated patient with severe dementia (RTE, 2017d). In her AED, the patient wrote that she wished to undergo euthanasia at her request, whenever she felt the time was right. The patient made many statements about wanting to die, but always tempered these with “but not now.” In reviewing her case, the Dutch euthanasia oversight body (the RTE) judged that the patient never orally requested euthanasia from the physician, and that the written directive was unclear (it appeared, from the AED, that she had always assumed she would be able to request euthanasia herself). Furthermore, the physician crossed a line by surreptitiously administering a sedative in the patient’s coffee to calm her before the procedure and by continuing despite the patient’s negative response during initiation of the infusion and administration of the euthanasic agent. The RTE concluded there should be no duress, or appearance of duress, during the provisioning of euthanasia (RTE, 2017d). In July 2018, the Regional Disciplinary Tribunal in The Hague reprimanded the physician for careless execution of euthanasia. Two key points made by the disciplinary judge were that: i) a written AED must be extremely clear, and ii) at the time of the euthanasia procedure, no matter how advanced the patient’s dementia, their views and their reaction to the situation must be considered (van Steenberg, 2018).

#### **4.4 SCENARIO 3: ADVANCE REQUESTS MADE BEFORE ANY DIAGNOSIS**

To be eligible for MAID in Canada, a person must have a grievous and irremediable medical condition (GC, 2016). However, a person can create an AR for MAID, in theory, at any time — before any diagnosis of illness, disease, or disability. Such a request would presumably make clear those situations the person imagines as intolerable, such as being unaware and reliant on artificial

nutrition and hydration, with little hope of recovery. Alternatively, through genetic testing or after witnessing the illness of a close family member, people might believe they have a heightened risk of developing a particular disease and wish to create an AR for MAID prior to any diagnosis.

In theory, an AR for MAID written before diagnosis would provide its maker with numerous opportunities to discuss end-of-life preferences with their loved ones and medical team. In this situation, an advance request could introduce the fact that a person considers MAID to be an end-of-life option. Under circumstances involving a sudden and unexpected decline, however, such as a car accident, an AR for MAID might function as a direct request. This latter scenario is described in Box 4.4, and illustrates questions that might arise when a request is created before diagnosis.

#### **Box 4.4**

#### **Advance Request for MAID Before Any Diagnosis: Em**

Em is a 29-year-old woman with no chronic health conditions. She has been an active proponent of MAID since she was a teenager and has volunteered in support of campaigns to raise public awareness. At the age of 20, she drafted an AR for MAID stating that she never wants to be kept alive in an incurable state of diminished mental and physical capacity where she cannot move or communicate, does not recognize her loved ones, and depends on care providers for basic needs such as eating and hygiene. At the same time, she also prepared an advance directive in which she named her older sister and brother as joint SDMs with equal power. When she prepared these documents and had her siblings sign them, they did not discuss them extensively.

Em receives a severe head injury in a car accident nine years later. She emerges from a coma after a month, but is left with profound neurological disabilities. Six months on, her physicians do not believe she can recover from this state. Em is able to breathe and swallow on her own but requires spoon-feeding. She is aware of her surroundings, but it is unclear whether she recognizes her five-year-old son. She can move her arms and hands voluntarily, follow simple commands (e.g., “turn your head”), and sometimes reply to simple questions by shaking or nodding her head. However, she cannot respond to more complex questions about her MAID preference or her degree of suffering, despite attempts by her siblings to understand these further. Em’s siblings bring her AR for MAID and advance directive to the attention of her healthcare team.

Several questions that could arise in this scenario have already been discussed because they could also arise in Scenarios 1 and 2. In fact, some of these issues could be exacerbated in the current scenario because when someone creates their AR for MAID without a particular disease or condition in mind, there may be even more uncertainty surrounding the content of the request and the timing of the procedure. Without a diagnosis, what should a person include in the AR for MAID (i.e., what circumstances would cause them intolerable suffering)? How could a person be fully informed of those conditions or circumstances with no specific experience of that situation? What information or experiences would inform such an AR for MAID? How would a healthcare practitioner, family member, or other third party responsible for the welfare of the patient interpret and act upon the request? These questions were considered in Scenario 2 so they will not be addressed again here. Instead, this section raises additional issues that might complicate individual cases further, as well as legal questions related to eligibility, implementation, and cross-jurisdictional applicability of ARs for MAID.

#### **4.4.1 Are Others Aware that the Patient’s AR for MAID Exists and Is It Accessible?**

Although they did not discuss its details, Em’s siblings were aware of her AR for MAID. If her family had no knowledge of its existence, then nobody involved in making Em’s medical decisions would know that she created a request for this very situation. Even if Em’s family were not aware of her AR for MAID, the hospital might be able to discover this information (e.g., through a MAID registry). Although Em’s siblings remember that she wrote an AR for MAID, they are not aware of its details and thus do not clearly understand the precise circumstances under which she might desire MAID. The importance of creating a clear AR for MAID and discussing the motivations behind the conditions described in the document is discussed in Section 4.3.2.

In Canada, Quebec is the only province or territory with a registry that includes the details of people’s advance medical directives (Box 3.1). These directives allow residents to “specify whether or not they consent to care that may be required by their state of health in the event they become incapable of giving consent” (Gov. of QC, 2014). MAID requests, however, cannot be included in advance medical directives (Gov. of QC, 2014). Alberta also has a personal directives registry that includes the maker’s contact information as well as the contact information of any person designated in the directive as an SDM (referred to as an *agent* in Alberta) (Gov. of AB, 2008b); however, information about the contents of the directive is not included.

Lack of access to the advance directives database has been raised as an issue by the Corporation des Paramédics du Québec (McDonald & Swain, 2017). To give patients the care they desire, paramedics would benefit greatly from immediate access to information about whether a patient consents to CPR or other life-saving measures (McDonald & Swain, 2017). Though instant access is less of an issue for MAID, which requires careful consideration, the point remains that documents about end-of-life care are not helpful unless they are easily available to those who will be using them to make decisions on behalf of incapacitated individuals.

#### **4.4.2 Would an AR for MAID Written in One Jurisdiction Apply in Another?**

What if Em had written her AR for MAID in Ontario but had since moved to Alberta? Would her request be legally valid in another province or territory? For advance directives, the answer to this question varies depending on the jurisdiction. Not only do provinces and territories have different regulations for advance directives (Section 5.1), they also have different rules about recognizing directives filed in other jurisdictions. In some jurisdictions, an advance directive is only recognized if it complies with the jurisdiction's own legislation, whereas in others it must comply with the legislation of the jurisdiction in which it was originally created (ALRI, 2017). Some jurisdictions recognize an advance directive in either of these situations and others have no legislation on this matter (ALRI, 2017).

To remedy this legislative patchwork, the Uniform Law Conference of Canada (ULCC) developed an act that, if adopted by all provinces and territories in Canada, would set uniform rules about interjurisdictional recognition of documents specifying an SDM (ULCC, 2016). As of December 2017, no provinces or territories had implemented the ULCC's act (ALRI, 2017). If legislation governing ARs for MAID were incorporated into Canada's existing advance directive legislation, rules surrounding the portability of ARs for MAID could be subject to the same heterogeneity issues that currently affect advance directives.

#### **4.4.3 Is the Patient's AR for MAID Recent Enough to Apply to Their Current Circumstances?**

Em drafted her AR for MAID when she was quite young, during a period in which she became passionate about empowering people to make their own healthcare choices. She never updated it and did not discuss MAID with her family members, so they are unsure how strongly she felt about it. Even if she wrote her request with great conviction, could we presume that her preferences regarding MAID stayed the same for almost 10 years? What if someone's

circumstances change considerably but they have not updated their AR for MAID to reflect these changes? Healthy people have little reason to suspect they will be in a situation that warrants MAID in the near future, unless affected by a sudden event. Frequent updating of their AR for MAID would likely not be a top priority. If they experience a significant life event, such as having a child (like Em) or caring for a terminally ill loved one, their MAID preferences might change.

#### 4.4.4 Who Decides When an AR for MAID Is Implemented?

Under the law, Em's two siblings have equal power over her healthcare. What if they disagree about whether Em's AR for MAID applies to her current situation? Perhaps Em's brother believes that she does not exactly meet the conditions in her AR because she is able to engage in basic communication and, in his opinion, recognize her son. Maybe he also argues that Em only wanted MAID if her condition was incurable, but thinks it is too early to know if she will recover. As one of her SDMs, would his opposition have any legal power? Or would the AR for MAID be legally binding, thus compelling third-party decision-makers to follow it, regardless of whether they agree?

ARs for MAID do not have any legal status in Canada, but people are able to indicate their wishes for future care and appoint a legally authorized SDM using an advance directive. Depending on the province or territory, the instructions in an advance directive may or may not be legally binding (Section 5.1). Even if they are not, when SDMs are directing the care of someone who lacks capacity, they are required by law to follow the instructions in a written directive (if they are applicable to the circumstances) (Figure 3.2). How might the written wishes of a patient, the views of a legally authorized SDM, the views of family members, and the opinions of healthcare practitioners be accommodated in the case of an AR for MAID? Would the family decide together with a physician that it is time to proceed with MAID, with the physician making the final judgment as to whether this is an appropriate decision?

In the Netherlands, guidance documents for patients and physicians on written euthanasia requests make it clear that written AEDs do not represent a guarantee that euthanasia will be performed (RTE, 2015c; KNMG *et al.*, 2016). Physicians must follow the due care criteria, which require them to be satisfied that the patient is experiencing unbearable suffering (Section 5.4.1). If the physician believes that this criterion has not been met, they cannot perform euthanasia without the risk of criminal prosecution. The guide specifically states that if a physician can no longer communicate with a patient and confirm their desire for euthanasia, there is a good chance the physician will not agree to perform the procedure (KNMG *et al.*, 2016).

#### 4.4.5 Do Patients Who Become Severely but Stably Incapacitated Raise Other Issues?

Em's head injury caused her to lose capacity suddenly. Although she has profound neurological disabilities, she does not have a degenerative condition and could therefore remain in this state for decades. Em's situation raises the question of whether an AR for MAID and a current request for MAID would have the same eligibility criteria. To be eligible for MAID under Canada's current legislation, a person must be "in an advanced state of irreversible decline in capability" (GC, 2016). Em is not technically declining; some patients like Em, and even some patients who have no awareness of their environment (e.g., those in a vegetative state), are "clinically stable following sudden-onset brain injury and are not otherwise 'dying'" (Kitzinger & Kitzinger, 2018). Thus, some brain injury patients might not fulfil the criterion of advanced, irreversible decline. It would be helpful to consider the applicability of this criterion in the context of ARs for MAID written with a brain injury in mind.

Em's situation adds an extra layer of complexity to the already difficult task of determining when a person meets the conditions of their AR for MAID. If someone were to write an informed AR for MAID after being diagnosed with a degenerative disease, there is a reasonable chance that they would specify conditions they would eventually meet; precisely *when* they met them would be the matter in question. Em's brother questions whether she meets the conditions described in her AR for MAID. If she does not, it is possible that she might not meet these conditions for many years because she is not in a state of decline. Without detailed and precise ARs for MAID, patients like Em could live in a state they would not have wanted to because their condition was not quite as severe as the one described in their request. It would be difficult, however, for someone to consider every possible outcome of a brain injury and include healthcare instructions for each one.

#### 4.4.6 How Might an AR for MAID and an Advance Directive for Withholding or Withdrawing Treatment Interact?

Em has both an AR for MAID and an advance directive. In her advance directive, she states that she wants life-sustaining measures (e.g., artificial nutrition and hydration) withdrawn if there is no chance that she can recover. After her brain injury, Em can eat on her own with assistance, but what if she needed a feeding tube? Which document would take legal precedence — the AR for MAID or the advance directive — or would it be the SDM's decision? The difference between a death following the withdrawal of a feeding tube and an assisted death (MAID) is certainly not a trivial consideration, and a request for MAID might reflect a patient's preference for one over the other (or their preference might be unclear).

Experiencing the death of a loved one might inform some people's decision to request MAID for themselves under similar circumstances. Qualitative research from the United Kingdom (where MAID is not permitted by law) found that relatives were deeply disturbed by the thought of their family member experiencing a prolonged death after removal of their feeding tube, even when healthcare practitioners assured them that palliative care would manage their loved one's pain (Kitzinger & Kitzinger, 2015). In contrast, relatives felt that assisted suicide would be a kinder, more compassionate, and more dignified option (Kitzinger & Kitzinger, 2015). In an interview study of 21 people from 12 different families in which a member died following withdrawal of artificial nutrition and hydration, most described the deaths as peaceful and calm, but many found the prolonged dying process, which generally took 9 to 14 days, burdensome and hard to witness (Kitzinger & Kitzinger, 2018). Some were distressed by their relative's physical appearance and others were upset that their loved one's wish to donate their organs could not be fulfilled (Kitzinger & Kitzinger, 2018). It may not be clear whether Em would have preferred her feeding tube withdrawn or MAID under her current circumstances, or whether a legal precedence exists for which document would take priority.

#### **4.5 SUMMARY OF UNCERTAINTIES IN ADMINISTERING ADVANCE REQUESTS FOR MAID**

This chapter identifies a range of considerations that could give rise to uncertainties in the administration of an AR for MAID. Most relate to one of three dimensions that together could influence the degree of complexity of any given AR for MAID: the state of the patient, the clarity of communication, and the strength of relationships. The *state of the patient* includes their present physical and/or emotional state, their current expressed desire for MAID, and the circumstances they describe as intolerable suffering in their AR for MAID. The *clarity of communication* reflects the extent to which a patient communicates their wishes throughout the process. Given the central role of third parties in administering ARs for MAID, the *strength of relationships* relates to the variability in familiarity and supportiveness of patient relationships with healthcare practitioners and loved ones. As shown in Figure 4.1, each dimension ranges from clear to unclear or strong to weak. An individual case could fall anywhere along each of these three axes; its position on each axis indicates the overall level of clarity and complexity.

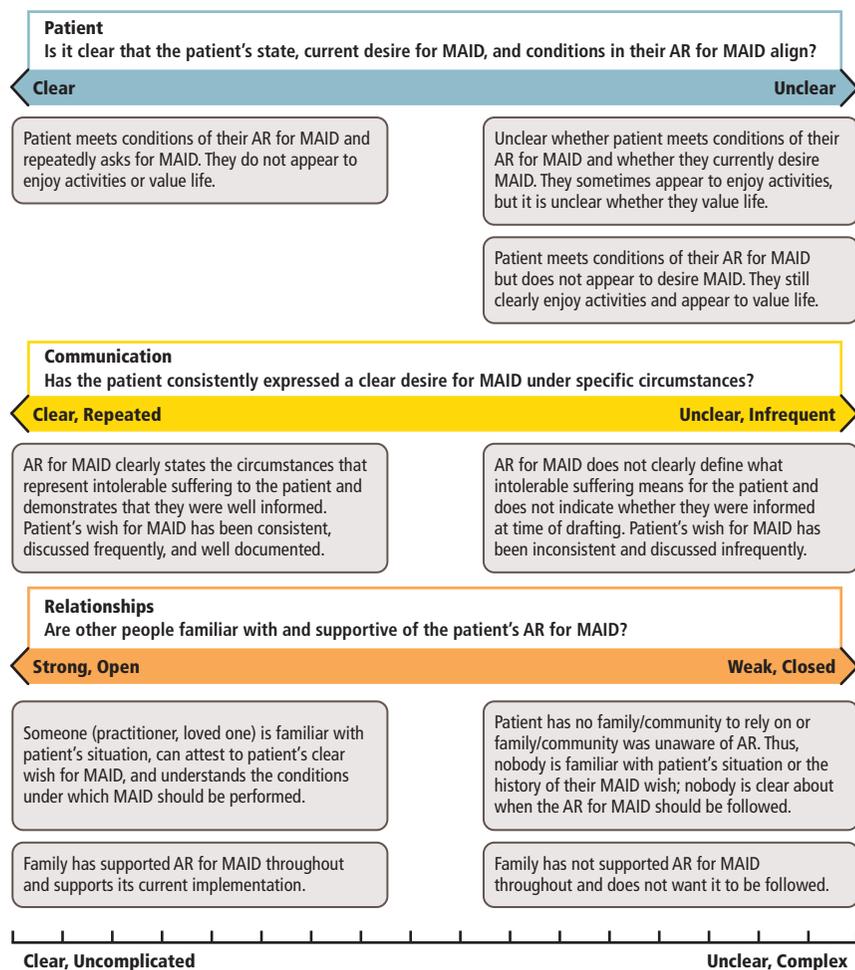


Figure 4.1

**Summary of Uncertainties in Administering Advance Requests for MAID**

The uncertainties that complicate the process of implementing each individual AR for MAID relate to one of three dimensions: (i) status of the patient (level of alignment between their current state, their current desire for MAID, and the conditions described in their AR for MAID); (ii) clarity of communication (how well the patient described the circumstances that represent intolerable suffering to them in their AR for MAID, how often they discussed their wishes, and how consistent these wishes were); and (iii) strength of relationships (whether the patient had strong and open relationships with their healthcare practitioners and loved ones, and whether at least one trusted person was familiar with and supportive of their AR for MAID). The figure assumes that the patient currently lacks the capacity to consent to MAID.

#### 4.5.1 Uncertainties Related to the Patient's State

The three scenarios illustrate how the timing and other circumstances of a person's AR for MAID might affect the level of uncertainty that could arise with respect to a patient's state. If an eligible patient with decision-making capacity created an AR for MAID to mitigate the risk of losing capacity prior to the procedure itself (Scenario 1), the short amount of time between drafting and implementation would likely reduce uncertainty. If an AR for MAID was created by a person diagnosed with a potentially grievous and irremediable medical

Table 4.2

Scenario Summary: Patient Variables That May Complicate an Advance Request for MAID

	Characteristic	Patient			
		Mo	Luc	Vi	Em
Pre-Implementation Phase (after AR for MAID is drafted)	Temporal scenario (1, 2, or 3)	<b>1</b> Already eligible	<b>2</b> After diagnosis, before eligibility	<b>2</b> After diagnosis, before eligibility	<b>3</b> Before diagnosis
	Currently eligible for MAID?	Yes	No	No	No
	Currently diagnosed with an illness?	Yes	Yes	Yes	No
Implementation Phase	Fulfils conditions of AR for MAID?	Yes	Yes	Will eventually fulfil (difficult to determine exactly <i>when</i> )	Some disagreement
	Time between drafting and implementation	Days	Months	Years	Years
	Expected cognitive state when AR for MAID is implemented	Fully unconscious	Conscious with severe cognitive impairment	Conscious with severe cognitive impairment	Conscious with severe cognitive impairment
	Stability of patient's preferences (i.e., do they still desire MAID)?	No current preferences (unconscious)	Preferences may have changed (though unlikely)	Preferences may have changed (and may be variable)	Preferences may have changed

condition but not yet eligible for MAID (Scenario 2), or not yet diagnosed at all (Scenario 3), there would be potential for greater uncertainty, particularly as more time elapsed between drafting and implementation. In Scenario 3, it might be difficult for a patient to predict the specific conditions that would make their AR for MAID relevant. In Scenarios 2 and 3, patients might not know how their condition would progress or how they would respond to their condition. Thus, they would be unable to predict the physical or psychological state they would be in when others were considering whether their AR for MAID was applicable to their condition. By comparing the patient vignettes used in this chapter, Table 4.2 reviews some of the variables related to a patient's state and desire for MAID.

#### **4.5.2 Uncertainties Related to Communication and Relationships**

There is a continuum of uncertainty with respect to the communication of a patient's desire for MAID and their relationships with relevant third parties. In many cases, patients would be able to control the specificity in their AR for MAID, the frequency with which they communicated their wishes, and the extent to which they ensured that a supportive person with whom they had a strong, open relationship was aware of their request and willing to help with its implementation. However, patients without family and community support could have difficulty identifying an SDM and accessing the help they need to prepare an AR for MAID.

Patients in Scenario 1, who made a clear and valid request for MAID at the time of their assessment and could speak for themselves throughout the assessment and approval process, create less uncertainty in the implementation of their AR for MAID. In contrast, the strength of communication and relationships prior to capacity loss might be very important for patients in Scenarios 2 and 3, since they would need to rely on others to interpret their AR for MAID and decide when (or whether) to implement it. With a clear, explicit, and comprehensive AR for MAID and effective communication with loved ones and physicians, patients could reduce some uncertainties that might arise when a request is not recent. For example, although patients diagnosed with a degenerative disease would be unable to predict its course, they could provide clarity for their healthcare practitioner and SDM by drafting a well-informed, detailed AR for MAID that considers the various trajectories the disease might take and by updating their AR and continuing to discuss it as their disease progressed.

## 4.6 CHAPTER SUMMARY

A person might choose to write an AR for MAID under a variety of circumstances, which are broadly covered by the three scenarios presented in this chapter — when already eligible for MAID, as a way to protect their eligibility if they lose capacity (Scenario 1); after diagnosis with a capacity-limiting condition, but before eligibility (Scenario 2); or before diagnosis, in case of a sudden event that removes their capacity and leaves them suffering intolerably (Scenario 3).

The scenarios illustrate how implementing a patient's AR for MAID could involve uncertainty, which mainly stems from the fact that the implementation process would require people to take steps to bring about another person's death at a time when that person could no longer confirm their wishes. There are three main sources of uncertainty, which include a patient's state and how well their current condition aligns with the circumstances described in their AR for MAID; the clarity of their communication about their request; and the strength of their relationships with trusted loved ones and their healthcare team prior to capacity loss. Depending on the level of uncertainty in each of these areas, ARs for MAID could be more or less complex to implement. The scenarios also illustrate some broader uncertainties that could arise beyond the level of individual cases, by asking how the stipulations in Canada's current MAID legislation might apply to ARs for MAID.

By identifying areas of uncertainty, the scenarios provide a starting point for a discussion of safeguards (Chapter 6). Some uncertainties related to the patient's condition would be difficult to mitigate. Uncertainties related to communication and relationships could be reduced by a well-informed AR for MAID that clearly defined the circumstances considered by the patient to represent intolerable suffering and frequent communication with those who would be involved in deciding when it should be followed.

# 5

## **Evidence from Related Practices in Canada and Abroad**

- **Legislation on Advance Directives in Canada**
- **Conflicts in the Use of Advance Directives in Canada**
- **Evidence on the Use of Advance Directives in Canada**
- **Overview of Advance Euthanasia Directives in Other Countries**
- **Advance Euthanasia Directives: How Are They Working in Practice?**
- **Euthanasia in Patients Without Decision-Making Capacity: Dutch Case Studies**
- **Chapter Summary**

## 5 Evidence from Related Practices in Canada and Abroad

### Key Findings

While no direct evidence exists on the use of ARs for MAID in Canada, some indirect evidence can be found in the practice of advance decision-making for healthcare in Canada and in the use of advance euthanasia directives in other countries.

Case law in Canada has established the priority of present consent over what is written in an advance directive, the priority of written instruction directives over best interests, and the authority of substitute decision makers to make end-of-life decisions.

A legal regime for ARs for MAID, established in federal criminal legislation, would form one part of the regulatory picture in Canada; practical implementation would depend on provincial and territorial legislation, as well as professional regulatory schemes.

The use of advance directives for healthcare has been limited, but is increasing in Canada. The evidence suggests that advance care planning and advance directives have occasionally positive, mostly equivocal, and no negative effects on patient outcomes.

The Benelux countries and Colombia allow some form of assisted death by advance request, though their use is rare and the eligibility criteria and safeguards differ by country.

Dutch cases that met due care criteria in the use of advance euthanasia directives tended to involve patients who had a number of well-documented discussions about their preferences with trusted physicians, and were consistent in their expressed desire for euthanasia, even after capacity loss.

Little empirical evidence exists on how well ARs for MAID work in practice. Belgium, Colombia, Luxembourg, and the Netherlands permit some form of AED, but only Belgium and the Netherlands have publicly available data on AEDs in the form of statistics or case reports. The transferability of this evidence to the Canadian context is complicated, however, by differences in legislative approaches to MAID and may be affected by differences in healthcare systems and professional practices.

Despite the lack of direct evidence, the Working Group considers some elements in healthcare law and practice in Canada as relevant and applicable to ARs for MAID. One such area is evidence related to advance consent in Canada, including legislative frameworks, clinical practice, and decision-making by people with capacity-limiting conditions. Other relevant bodies of evidence are (i) the legislation regulating advance directives and their clinical application, and (ii) the broader clinical practice of ACP and its relationship to advance directives.

This chapter reviews such evidence and identifies considerations relevant to ARs for MAID. The first half of the chapter situates ARs for MAID in the current Canadian context of healthcare decision-making. The second half situates them in the international context of AEDs, which provides the only available evidence on the practice of making and following an advance directive for euthanasia.

## **5.1 LEGISLATION ON ADVANCE DIRECTIVES IN CANADA**

ARs for MAID are not valid in Canada, as a person is required to express consent immediately prior to the MAID procedure (GC, 2016). However, advance directives are a mechanism in Canada by which people can direct their future care, allowing them to have their treatment preferences and decisions known and respected in the event they lose decision-making capacity. Because Canadian legislation on advance directives may be relevant to ARs for MAID, this section begins with a review of the legislation.

With the exception of Nunavut, all Canadian provinces and territories have their own legislation that regulates healthcare decision-making for people who lack the capacity to make decisions themselves. The details of these laws vary by jurisdiction. Table 5.1 summarizes the legislation governing advance directives, including instruction directives and proxy directives, in each province and territory.

Table 5.1  
Provincial and Territorial Legislation Governing Advance Directives

Jurisdiction	Terminology and Legislation for Instruction Directives	Limits of Instruction Directives Under the Law	Terminology and Legislation for Proxy Directives	Limits of Proxy Directives Under the Law
British Columbia	<ul style="list-style-type: none"> <li>Referred to as <b>advance directives</b></li> <li>Legislated by the <i>Healthcare (Consent) and Care Facility (Admission) Act, RSBC 1996, c. 181</i></li> <li>Must be in writing, signed, dated, two witnesses (one if the witness is a notary public)</li> <li>Maker must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>Instructions in an advance directive to either do anything that is prohibited by law, or to omit to do anything that is required by law, are not valid</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>representative</b></li> <li>Legislated by the <i>Representation Agreement Act, RSBC 1996, c. 405</i></li> <li>Must be in writing, signed, two witnesses</li> <li>Representative must be at least 19 years old</li> <li>For a representation agreement to be effective, additional forms (called certificates) are required</li> </ul>	<ul style="list-style-type: none"> <li>A representative cannot consent to sterilization for non-therapeutic purposes</li> <li>A representative cannot refuse admission to a facility or the provision of professional services, care or treatment under the <i>Mental Health Act</i></li> </ul>
Alberta	<ul style="list-style-type: none"> <li>Referred to as <b>personal directives</b></li> <li>Legislated by the <i>Personal Directives Act, RSA 2000, c. P-6</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>Maker must be at least 18 years old</li> </ul>	<ul style="list-style-type: none"> <li>Personal directives cannot include instructions relating to aided suicide, euthanasia, or other instructions prohibited by law</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as an <b>agent</b></li> <li>Legislated by the <i>Personal Directives Act, RSA 2000, c. P-6</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>Agent must be at least 18 years old</li> </ul>	<ul style="list-style-type: none"> <li>An agent cannot make decisions regarding psychosurgery, sterilization that is not medically necessary, tissue removal for transplantation or research, or participation in research*</li> </ul>
Saskatchewan	<ul style="list-style-type: none"> <li>Referred to as <b>health care directives</b></li> <li>Legislated by the <i>Health Care Directives and Substitute Health Care Decision Makers Act, 2015, c. H-0.002</i></li> <li>Must be in writing, signed, and dated, but witnesses not required</li> <li>Maker must be at least 16 years old</li> </ul>	<ul style="list-style-type: none"> <li>A health care directive cannot be used to consent to active euthanasia or assisted suicide</li> <li>A decision that is prohibited by the <i>Criminal Code</i> cannot be made based on a health care directive</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>proxy</b></li> <li>Legislated by the <i>Healthcare Directives and Substitute Healthcare Decision Makers Act, 2015 c. H-0.002</i></li> <li>Must be in writing, signed, dated, but witnesses not required</li> <li>Proxy must be at least 18 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>

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Jurisdiction	Terminology and Legislation for Instruction Directives	Limits of Instruction Directives Under the Law	Terminology and Legislation for Proxy Directives	Limits of Proxy Directives Under the Law
Manitoba	<ul style="list-style-type: none"> <li>Referred to as <b>health care directives</b></li> <li>Legislated by the <i>Health Care Directives Act, CCSM 1993, c. H27</i></li> <li>Must be in writing, signed, and dated, but witnesses not required</li> <li>Maker must be at least 16 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>proxy</b></li> <li>Legislated by the <i>Health Care Directives Act, CCSM 1993, c. H27</i></li> <li>Must be in writing, signed, and dated, but witnesses not required</li> <li>Proxy must be at least 18 years old</li> </ul>	<ul style="list-style-type: none"> <li>A proxy cannot consent to: medical treatment for research purposes, sterilization that is not medically necessary, or tissue removal for transplantation or research*</li> </ul>
Ontario	<ul style="list-style-type: none"> <li><i>Health Care Consent Act, SO 1996, c. 2</i> contains no specific legislation on instruction directives, but does recognize the <i>wishes</i> made by a person while capable</li> <li>Wishes may be expressed in writing, orally, or in any other manner and witnesses not required</li> <li>No age specified**</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as an <b>attorney for personal care</b> or <b>substitute decision maker</b></li> <li>Legislated by the <i>Substitute Decisions Act, 1992, SO 1992, c. 30</i></li> <li>Must be in writing, signed, dated, two witnesses</li> <li>Attorney for personal care must be at least 16 years old</li> </ul>	<ul style="list-style-type: none"> <li>An attorney for personal care cannot consent to: use of electric shock as aversive conditioning, medical treatment for research purposes, sterilization that is not medically necessary, or tissue removal for transplantation</li> </ul>
Quebec	<ul style="list-style-type: none"> <li>Referred to as <b>advance medical directives</b></li> <li>Legislated by <i>An Act Respecting End-of-Life Care, SQ 2014, c. 2</i></li> <li>Must be in writing, signed, dated, and given by notarial act <i>en minute</i> or in the presence of two witnesses on a prescribed form</li> <li>Maker must be at least 18 years old</li> </ul>	<ul style="list-style-type: none"> <li>An advance medical directive may not be used to request medical aid in dying</li> <li>Covers the following end-of-life situations: CPR, artificial ventilation (respirator), dialysis, forced feeding and hydration, and artificial nutrition and hydration</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>mandatory***</b></li> <li>Legislated by the <i>Civil Code of Quebec, SQ 1991, c. 64</i> in a protection mandate</li> <li>Must be made by notarial act <i>en minute</i> or in the presence of two witnesses</li> <li>Mandatory must be at least 18 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>

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Jurisdiction	Terminology and Legislation for Instruction Directives	Limits of Instruction Directives Under the Law	Terminology and Legislation for Proxy Directives	Limits of Proxy Directives Under the Law
New Brunswick	<ul style="list-style-type: none"> <li>Referred to as <b>health care directives</b></li> <li>Legislated by the <i>Advance Health Care Directives Act, SNB 2016, c. 46</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>No age specified**</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>proxy</b></li> <li>Legislated by the <i>Advance Health Care Directives Act, SNB 2016, c. 46</i></li> <li>Proxy must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>
Nova Scotia	<ul style="list-style-type: none"> <li>Referred to as <b>personal directives</b></li> <li>Legislated by the <i>Personal Directives Act, SNS 2008, c. 8</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>No age specified**</li> </ul>	<ul style="list-style-type: none"> <li>An instruction in a personal directive that is prohibited by law is void</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>delegate</b></li> <li>Legislated by the <i>Personal Directives Act, SNS 2008, c. 8</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>Delegate must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>
Prince Edward Island	<ul style="list-style-type: none"> <li>Referred to as <b>health care directives</b></li> <li>Legislated by the <i>Consent to Treatment and Health Care Directives Act, RSPEI 1988, c. C-17.2</i></li> <li>Must be in writing, signed, and dated, but witnesses not required</li> <li>Maker must be at least 16 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>proxy</b></li> <li>Legislated by the <i>Consent to Treatment and Health Care Directives Act, RSPEI 1988, c. C-17.2</i></li> <li>Must be in writing, signed, and dated, but no witnesses required</li> <li>Proxy must be at least 16 years old</li> </ul>	<ul style="list-style-type: none"> <li>A proxy cannot consent to: medical treatment for research purposes, sterilization that is not medically necessary, abortion that is not medically necessary, or the use of electric shock as aversive conditioning</li> </ul>

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Jurisdiction	Terminology and Legislation for Instruction Directives	Limits of Instruction Directives Under the Law	Terminology and Legislation for Proxy Directives	Limits of Proxy Directives Under the Law
Newfoundland and Labrador	<ul style="list-style-type: none"> <li>Referred to as <b>advance health care directives</b></li> <li>Legislated by the <i>Advance Health Care Directives Act, SNL 1995, c. A-4.1</i></li> <li>Must be in writing, signed, two witnesses</li> <li>Maker must be at least 16 years old****</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>substitute decision maker</b></li> <li>Legislated by the <i>Advance Health Care Directives Act, SNL 1995, c. A-4.1</i></li> <li>Must be in writing, signed, two witnesses</li> <li>Substitute decision maker must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>A substitute decision maker cannot consent to: medical treatment for research purposes, sterilization that is not medically necessary, or tissue removal for transplantation or research*</li> </ul>
Yukon	<ul style="list-style-type: none"> <li>Referred to as <b>directives</b></li> <li>Legislated by the <i>Care Consent Act, SY 2003, c. 21</i>,</li> <li>Must be in writing, signed, dated, two witnesses</li> <li>Maker must be at least 16 years old</li> </ul>	<ul style="list-style-type: none"> <li>None stated</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as a <b>proxy</b></li> <li>Legislated by the <i>Care Consent Act, SY 2003, c. 21</i></li> <li>Must be in writing, signed, and dated, two witnesses</li> <li>Proxy must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>A proxy cannot consent to the provision of health care to a person for the purposes of sterilization*</li> </ul>
Northwest Territories	<ul style="list-style-type: none"> <li>Referred to as <b>personal directives</b></li> <li>Legislated by under the <i>Personal Directives Act, SNWT 2005, c.16</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>Maker must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>A provision in a personal directive has no legal effect if it provides for transfer of property or management of financial affairs, or if it is prohibited by law</li> </ul>	<ul style="list-style-type: none"> <li>Authorized decision-maker referred to as an <b>agent</b></li> <li>Legislated by the <i>Personal Directives Act, SNWT 2005, c. 16</i></li> <li>Must be in writing, signed, dated, one witness</li> <li>Agent must be at least 19 years old</li> </ul>	<ul style="list-style-type: none"> <li>An agent cannot consent to: sterilization that is not medically necessary, tissue removal for transplantation or research, psychosurgery, participation in research, any prescribed health care not authorized expressly in the personal directive*</li> </ul>

Source: Gov. of PE, 1988; Gov. of QC, 1991, 2014, 2017b; Gov. of ON, 1992, 1996, 2012; Gov. of MB, 1993a; Gov. of NL, 1995; Gov. of BC, 1996a, 1996b; Gov. of AB, 2000; Gov. of YK, 2003b; Gov. of NT, 2005; Gov. of NS, 2008, 2010; Gov. of SK, 2015; Gov. of NB, 2016; Educaloi, n.d.

**Notes for Table 5.1**

\* The legislation states that SDMs may not make decisions on these matters unless the directive provides instructions for doing so.

\*\* In New Brunswick and Nova Scotia, the legislation does not state a specific age; rather, it states that people with the capacity to make decisions may make instruction directives. Because Ontario's *Health Care Consent Act* does not use any language with respect to healthcare directives, advance consent, advance directives, etc. (except for stating that a person may express treatment wishes while capable), it does not make any statements connecting capacity with the ability to make an instruction directive.

\*\*\* The *Civil Code of Quebec* allows adults with capacity to prepare a protection mandate in which they may describe how they would like themselves and their property to be looked after in case they lose capacity. Within this mandate, they may also designate a mandatary (the person responsible for ensuring that the conditions of their mandate are followed). Although wishes regarding end-of-life care may be included in a protection mandate, the wishes expressed in an advance medical directive take priority over those expressed in a mandate (Gov. of QC, 2017b).

\*\*\*\* Newfoundland and Labrador's *Advance Health Care Directives Act* states that a person younger than 16 is presumed to lack the capacity to make healthcare decisions, but if there is evidence to the contrary, they may be allowed to make an advance healthcare directive.

In all provinces and territories in Canada (except Nunavut), proxy directives are legally binding documents. Instruction directives are also legally binding in most provinces and territories (e.g., ELPC, 2016a, 2016b, 2016c); that said, their application depends on how relevant the written instructions are to the specific medical situation. In British Columbia, for example, an advance directive does not apply if a healthcare practitioner reasonably believes that the instructions do not pertain to the decision at hand; the instructions are unclear; the directive does not reflect significant changes that have occurred in the maker's wishes, values, or beliefs; or, since the directive was written, there have been significant medical advances that might benefit the maker (Gov. of BC, 1996a). Furthermore, in emergencies, healthcare practitioners are not required to locate and consult advance directives before providing life-saving treatments, but must respect refusals of treatment made in advance of loss of capacity if they are aware of them (ONCA, 1990).

Although terms such as advance directive, advance care plan, and advance consent are used in common language in Ontario, the *Health Care Consent Act* does not define these terms (HPCO, 2016). The Ontario Act does not include a mechanism to provide legally binding advance consent to treatment; healthcare practitioners must always obtain consent from a capable patient, or, if the patient is incapable, from a valid SDM (HPCO, 2016). However, SDMs are required to make decisions based on the patient's wishes, if they are known, or on the patient's best interests, if they are not known (e.g., CCB, 2017). In addition,

the Ontario Act indicates that healthcare practitioners must respect advance refusals of treatment if they are made aware of them (Gov. of ON, 1996), which is consistent with the position taken by the Ontario courts (see Section 5.2.1).

## 5.2 CONFLICTS IN THE USE OF ADVANCE DIRECTIVES IN CANADA

In the Working Group's clinical experience, most conflicts over healthcare decisions are resolved at the bedside. As such, short of academic research on the effectiveness of advance directives (Section 5.3.2), issues and conflicts arising from their use in Canada are generally not made public. If an issue or conflict cannot be resolved at the bedside, patient advocates and ethics committees in hospitals may be brought in to support family consultations and achieve resolution, though the content and outcomes of these consultations are not public knowledge.

All provinces and territories have professional regulatory bodies that evaluate formal complaints against their membership; Ontario has additionally created a Consent and Capacity Board (CCB) to resolve disputes outside of the court system (Gov. of ON, 1996). When all else fails, the court system can be the final arbiter in a conflict concerning the implementation of an advance directive. This section reviews conflicts involving advance directives as available from these sources.

### 5.2.1 Case Law on Advance Directives in Canada

Few cases related to advance directives make it to the courts. A search of the Canadian Legal Information Institute (CanLII) database on August 31, 2018, returned 10 court cases with the exact phrase *advance directive* in the body of the text. Only four of these directly related to conflicts with the application of advance directives: *Malette v. Shulman* (ONCA, 1990), *Van Wijngaarden v. Tzalis* (ONCA, 1997), *Cuthbertson v. Rasouli* (SCC, 2013), and *Bentley v. Maplewood Seniors Care Society* (BCSC, 2014; BCCA, 2015). A subsequent search of the exact phrase *personal directive* turned up 64 court cases in the CanLII database, only 2 of which concerned written directives: *Sweiss v. Alberta Health Services* (ABQB, 2009) and *B.M. v. K.S.* (NSSC, 2015). The remaining cases involved conflicts and disputes over the appointment of an SDM or a will regarding a person's estate; some cases mentioned the phrase tangentially, or to note the absence of such a document.

### Case Law Establishes the Priority of Present Consent

Regardless of what is written in an advance directive, the present expressed consent to (or refusal of) treatment takes priority. For example, the case of *Van Wijngaarden v. Tzalais* was made moot by the appellant regaining competency to express her wishes and leaving the care of the respondents (ONCA, 1997).

Another case, *Bentley v. Maplewood Seniors Care Society*, reiterated that present consent overrules prior written directives, stating that “caregivers must give effect to patients’ wishes in the ‘here and now’, regardless of prior directives” (BCCA, 2015). Mrs. Bentley had advanced Alzheimer’s disease and lived at a care facility run by the Maplewood Seniors Care Society. Her family asked the care providers to stop providing water and food to Mrs. Bentley, per her prior written directives. The care providers demonstrated that Mrs. Bentley accepted food and water with assistance (e.g., spoon-feeding, holding a glass to her lips), and therefore believed she was consenting to the assisted nourishment — they refused to stop providing that service (BCSC, 2014). The chambers judge found that assisting feeding by holding a spoon or glass to one’s mouth is personal care, not healthcare, and therefore the *Health Care (Consent) and Care Facility (Admission) Act* (Gov. of BC, 1996a) does not apply in this situation. Furthermore, the chambers judge and the appeal judge sided with the Maplewood Seniors Care Society, stating that Mrs. Bentley was implicitly consenting by opening her mouth to eat or drink when a spoon or glass was held to her lips (BCCA, 2015).

### Case Law Establishes the Priority of Written Instruction Directives over Best Interests

Written directives, as they are medically relevant to the circumstances, take priority over the best interests of the patient as determined by a third party, such as the healthcare practitioner or SDM. *Malette v. Shulman* established the validity of advance refusal of treatment, even in life-threatening situations (ONCA, 1990). Mrs. Malette carried a card in her wallet that identified her as a Jehovah’s Witness, stating that she was to be given no blood transfusion under any circumstances. A nurse discovered the card and brought it to the physician’s attention, who then decided to give Mrs. Malette a blood transfusion anyway. The judge determined that, regardless of the good intentions of the physician to save Mrs. Malette’s life, the card she carried was valid refusal of a blood transfusion, and the physician was liable for damages for battery (ONCA, 1990).

*Swiss v. Alberta Health Services* also held that, when they are available, patient directions and instructions prevail over best interest judgments by healthcare practitioners (ABQB, 2009). Mr. Swiss signed an advance directive, stating that he wished for Islamic rules to be followed in his healthcare decision-making.

Mr. Swiss suffered significant brain damage following a cardiac arrest, and was placed on a mechanical ventilator. His physician and a consulting neurologist both concluded that there was no chance of recovery and that keeping him on a ventilator would only cause him further suffering; the physician recommended removing mechanical ventilation support and signing a DNR order. After being informed that a DNR order had been put in place at the hospital, Mr. Swiss' family filed to have it removed and sought an injunction to keep Mr. Swiss on mechanical ventilation. The court granted the injunction to maintain mechanical ventilation, stating that this decision was in the best interest of Mr. Swiss because it respected his wishes and beliefs, was consistent with Islamic Law, and would allow his family to obtain an independent assessment of his condition. However, the court kept the DNR order, stating that it was in the patient's best interest not to have CPR performed and that the DNR order was consistent with Mr. Swiss' wishes. An agreement was reached between the physician and the family to remove the mechanical ventilator, and Mr. Swiss passed away in October 2009. In his judgment of the case, Vital O. Ouellette, J.C.Q.B.A. stated: "Given the mandatory wording of s. 19(1) of the *Personal Directives Act*, it appears that where a personal directive with clear instructions conflicts with recommended medical treatment, the wishes, directions and instructions of the patient will prevail" (ABQB, 2009).

The priority of written directives over best interest arguments extends beyond healthcare in some provinces and territories. For example, *B.M. v. K.S.* in Nova Scotia resolved a dispute over whether to move the applicant B.M.'s mother (Mrs. L) to a nursing home closer to his home, despite her personal directive stating her wish to live in her own home for the remainder of her life (NSSC, 2015). Mrs. L set up a trust and power of attorney to ensure funds were available to pay for the care needed for her to remain in her home; K.S. was the co-attorney named in the power of attorney. The judge ruled that Mrs. L's personal directive was to be followed, regardless of her son's wish to act in her "best interests" and move her to a nursing facility closer to his home (NSSC, 2015).

### Case Law Establishes the SDM's Authority at End-of-Life

If an SDM acts in accordance with the known wishes or, if unknown, the best interests of the patient, they have authority regarding end-of-life decision-making. *Cuthbertson v. Rasouli* established that withdrawal or withholding of life support constitutes medical treatment (under Ontario's *Health Care Consent Act*) and therefore, the SDM has the legal authority to consent to (or refuse) the removal or withholding of life support (SCC, 2013). The patient in this case was in an unconscious state and on life support for three years; his physicians wanted to remove mechanical ventilation and life support. He had

not expressed a prior capable wish about such a circumstance. The SDM (the patient's wife) refused to provide consent and the physicians declared they did not need consent, since, they argued, removal of life support is not medical treatment. The Ontario Superior Court of Justice sided with the SDM, stating that SDMs have the legal authority to consent to the removal or withholding of life support; if no consent is forthcoming, physicians may petition for a ruling by the CCB. The ruling was appealed to the Supreme Court of Canada, but the appeals were dismissed, confirming the authority of the SDM to make life-ending (or prolonging) choices in accordance with their interpretation of the will or best interests of the patient (SCC, 2013).

### 5.2.2 Advance Directives Dispute Resolutions Outside of the Courts

Family members can pursue unresolved disputes over the treatment of patients with an advance directive by lodging a complaint with regulatory or other tribunals. Regulatory tribunals enforce standards of care and the professional conduct of their members through licensing; Ontario's CCB provides legally binding resolution to disputes related to consent and capacity outside of the court system (Choong *et al.*, 2010).

As far as the Working Group is aware, very few cases involving disputes over advance directives are brought before these tribunals. For example, Ontario's CCB received 7,770 applications to resolve disputes in the 2016 to 2017 reporting year; of those, 4,474 hearings were held (CCB, 2018). The vast majority of applications involved issues of involuntary status (46%), capacity to consent (26%), or community treatment orders (21%), and a small proportion handled issues that may have arisen from conflicts with advance directives, such as compliance with the principles of substitute decision-making (0.5%) (CCB, 2018).

A family member concerned about a physician's treatment of their relative can make a formal complaint to their respective provincial or territorial College of Physicians and Surgeons. Very few of these complaints, however, have involved advance directives. For example, the College of Physicians and Surgeons of Ontario (CPSO) received 4,946 complaints in 2016 (CPSO, 2017a), of which 46 cases concerning professional misconduct and/or incompetence were proved before its Discipline Committee (CPSO, 2017a). Through a personal communication with the CPSO, the Working Group confirmed that none of these cases involved issues with an advance directive.

A search of the CanLII database for tribunal cases with the exact phrase *advance directive* or *personal directive*, conducted on August 31, 2018, returned 13 cases total, of which 2 were about the resolution of a dispute over written directives for healthcare. The first case, *E.G.J.W. v. M.G.C.* (HPARB, 2014), was brought before Ontario’s Health Professions Appeal and Review Board after a decision by the CPSO to pursue no further action following a complaint. A patient’s SDM had requested a “Full Code” (full resuscitation) order, which was revoked and replaced by a DNR order without consulting the SDM; the Board found that the physicians were required to obtain consent and recommended the CPSO revise its policies to ensure compliance with the *Health Care Consent Act* (Gov. of ON, 1996; HPARB, 2014).

The second case, *L.L. (Re)*, was brought before the CCB (CCB, 2017). It involved an 88-year-old man (L.L.) with advanced dementia. In L.L.’s Power of Attorney for Personal Care, he named his daughter as his SDM. He also set out specific instructions requesting to be allowed to die with appropriate means taken to alleviate suffering, in the event of severe mental or physical disability with no reasonable expectation of recovery. The SDM and care team disagreed about the level of treatment intervention appropriate for L.L. The CCB’s decision confirmed that an SDM is required to make choices in compliance with the known prior capable wishes of the patient before weighing best interests, or else they could be removed as SDM because they are not meeting the requirements of the role (Gov. of ON, 1996; CCB, 2017).

### **5.3 EVIDENCE ON THE USE OF ADVANCE DIRECTIVES IN CANADA**

#### **5.3.1 Limited but Increasing Use of Advance Directives in Canada**

In the early 1990s, a survey of policies in Canadian hospitals (n=697 responding facilities) found that only 10 (2.6%) of the 388 hospital policies received from respondents addressed advance directives (Rasooly *et al.*, 1994). At that time, only four provinces (Manitoba, Ontario, Quebec, and Nova Scotia) had passed legislation on advance directives (Rasooly *et al.*, 1994). In the late 1990s, the average rate of completion of an advance directive in Canada was approximately 10% (Sawchuck & Ross-Kerr, 2000) and 35% of 306 nurses surveyed in Quebec had cared for a patient with an advance directive (Blondeau *et al.*, 2000).

Since that time, all provinces and territories (except Nunavut) have passed legislation regarding advance directives for healthcare (Gilmour, 2017). In a mailed survey, conducted between September 2007 and April 2009, which received responses from 2,060 people in Canada, including 679 older adults, approximately half of these older adults had expressed healthcare wishes in a written document, while almost 70% had discussed these wishes with family (Bravo *et al.*, 2011). A 2011 survey of 1,104 adult patients aged 18 to >80 in a family care practice in Hamilton, Ontario, found that 20% of the 800 respondents had written advance directives, and 44% had previously discussed them with another person (O'Sullivan *et al.*, 2015). However, over 75% of respondents in this survey rated advance directives as at least somewhat important. Of those who had discussed advance directives, the vast majority (90%) had done so with their families and friends while only 10% had done so with their family doctors (O'Sullivan *et al.*, 2015). A 2012 online opinion poll surveying 1,523 respondents (1,021 from all provinces, and an additional 502 residing specifically in the Fraser Health Authority in British Columbia) found that, while approximately 16% of respondents knew the term *advance care planning*, 52% had discussed ACP with family or friends, 10% had discussed ACP with healthcare practitioners, and 20% had written an advance directive (Teixeira *et al.*, 2015).

Taken together, the evidence suggests that a majority of adults in Canada discuss future care with their families, but a minority have those discussions with healthcare practitioners or formally document their preferences, with about 20% of adults expressing their healthcare preferences in writing.

### 5.3.2 Advance Directives and ACP: Respecting Healthcare Values and Preferences

Studies of advance directives are often included in research on ACP since the completion of an advance directive is one of the metrics for examining the effectiveness of ACP. For the purposes of this report, advance directives are considered within the broader evidence on ACP, though studies specifically on advance directives are noted where available.

Measurements of the effectiveness of ACP and advance directives vary by study, complicating the interpretation of what success or effectiveness means. A 2015 systematic review identified lower rates of hospitalization, more deaths occurring in nursing homes (than in hospitals), and higher rates of treatment consistent with patient wishes as the most common evidence for the effectiveness of ACP interventions for nursing home residents (Martin *et al.*, 2016). However, this review also notes that there are very few studies on ACP with high-quality methodology and there is a lack of randomized controlled trials.

### Systematic Reviews and Meta-Analyses on the Effectiveness of ACP or Advance Directives

A systematic review and meta-analysis of 55 randomized controlled studies on ACP efficacy found that ACP increases the completion rate of advance directives, the number of end-of-life discussions, and the concordance between patient preferences and the healthcare delivered (Houben *et al.*, 2014). The effect of ACP on the quality of communication, satisfaction with care, decisional conflicts, and patient symptoms (e.g., anxiety, depression, well-being, pain) was equivocal; approximately equal numbers of studies that examined these outcomes found positive or neutral effects, with no studies recording negative effects (Houben *et al.*, 2014).

Another systematic review of 113 experimental and observational studies of ACP supports these findings; however, while the review notes some evidence of a positive effect of ACP on satisfaction with end-of-life care, it cautions that there is much variation in the methods used to measure outcomes and in the outcomes themselves (Brinkman-Stoppelenburg *et al.*, 2014). Indeed, in a systematic review of 37 published articles measuring knowledge of ACP, Kernel-Schiffman and Werner (2017) note a need to develop validated tools to measure objective and subjective knowledge of the practice as a first step to increasing awareness among professionals and lay people.

ACP is more effective if it includes more than just written instructions; in particular, Brinkman-Stoppelenburg *et al.* (2014) found that a patient's wishes are more likely to be complied with if they have conversations with their family and care team about care planning and the goals of care. None of the reviewed studies found adverse effects (e.g., increased stress, anxiety, or depression) in patients and families who participated in ACP (Brinkman-Stoppelenburg *et al.*, 2014). A recent Delphi panel consensus of 52 multidisciplinary, international ACP experts (including six members from Canada) identified overarching outcomes for successful ACP (Sudore *et al.*, 2018). The top five outcomes were: (i) receiving care consistent with goals, (ii) choosing and (iii) documenting the choice of an SDM, (iv) discussing values and care preferences with the SDM, and (v) documenting values and care preferences prior to capacity loss (Sudore *et al.*, 2018).

A systematic review of 18 studies examining ACP by patients with dementia noted general positive outcomes and effects for both patients and caregivers (Dixon *et al.*, 2018). Of 53 measured outcomes across the 18 studies, 41 were positively associated with ACP and the remaining 12 outcomes showed ACP had no effect (Dixon *et al.*, 2018). For example, with ACP, deaths more often occurred in

a preferred location (three out of four studies), patients spent fewer days in hospital (five out of five studies), and patients reported less emotional distress (two out of two studies) (Dixon *et al.*, 2018). This systematic review included 13 of the same studies examined by Brinkman-Stoppelenburg *et al.* (2014), discussed above.

Dening *et al.* (2011) reviewed 17 empirical studies on ACP by people with dementia, and found that the likelihood of this population making ACP decisions for themselves was lower than in other illness groups. This may be because, for people with dementia, it is difficult to predict when cognition will decrease and ACP will no longer be feasible (Dening *et al.*, 2011). A synthesis of five qualitative studies supports the finding that ACP by people with dementia is low compared with those with other conditions (Ryan *et al.*, 2017). Ryan *et al.* (2017) found that hesitation to initiate ACP and a preference for informal approaches to planning influences the uptake of ACP in this population. A systematic review of ACP initiation in patients with dementia identified family and caregiver willingness or reluctance as dominant factors in ACP initiation (van der Steen *et al.*, 2014). Factors such as ethnic minority status, family distance, and healthcare system factors such as continuity of care also influenced the initiation of ACP by patients with dementia (van der Steen *et al.*, 2014).

### Studies on the Effectiveness of ACP and Advance Directives in Canada

Studies on the effectiveness of ACP in Canada are limited, as the majority of research that the Working Group identified focuses on the effectiveness of programs or tools for engagement in ACP (e.g., [www.acpcrio.org](http://www.acpcrio.org)) rather than the outcomes for those who participate in ACP. For example, Heyland *et al.* (2013) conducted surveys to examine the engagement of hospitalized elderly patients in ACP. Of elderly patients who were at high risk of dying in the next six months ( $n=278$ ) and their family members ( $n=225$ ) from 12 acute care hospitals in Canada, a majority had thought about end-of-life care (76.3%) and had formally named an SDM (73.3%). However, rates for the communication of these preferences to healthcare providers and the accurate documentation of those preferences in medical records were lower (approximately 30% of the time for either) (Heyland *et al.*, 2013). When preferences were documented in a Goals of Care order, the documented preferences did not match the expressed preferences of the patient 70% of the time — the most extreme example being that 28% of patients expressed a preference for comfort measures only, but this preference was documented in only 4.5% of Goals of Care orders (Heyland *et al.*, 2013).

In a randomized controlled trial of 1,292 residents in six nursing homes in Ontario between 1994 and 1998, Molloy *et al.* (2000) found that those with advance directives were less likely to be hospitalized, and spent less time in hospital, than those without advance directives. However, they also found no difference in mortality rates or satisfaction with care between those with an advance directive and those without one (Molloy *et al.*, 2000).

Studies on interventions to increase ACP in Quebec found that having a care plan did not improve the ability of an SDM to predict an older adult's preference in hypothetical health and research scenarios (Bravo *et al.*, 2016a, 2016b). SDMs underestimated the quality of life of the older adults surveyed, leading to differences in treatment decisions for hypothetical health scenarios (Bravo *et al.*, 2017b). However, older adults who participated in the ACP experiment were highly satisfied with the process (Bravo *et al.*, 2016a).

A retrospective analysis of the medical charts of 299 patients who died in three Quebec hospitals found that few contained formal documentation of patients' end-of-life wishes (Frenette *et al.*, 2017). Ten of the 299 charts contained a power of attorney (3.3%) and five (1.7%) contained a copy of the patient's advance directive (Frenette *et al.*, 2017). However, this study focused on the use of a hospital-specific tool for documenting end-of-life care preferences: the Levels of Intervention (LOI) form, which was present in 209 of the 299 charts. The LOI form is comparable to a Goals of Care order in that it is completed by the healthcare team, most often (but not always) in consultation with the patient or their relatives (Frenette *et al.*, 2017). Frenette *et al.* (2017) found that, for those charts containing LOI forms, 98.7% were respected at the time of death.

A review of practices in Ontario found wide variation in the kinds of practical discussions surrounding ACP, goals of care, and healthcare consent (Wahl *et al.*, 2016). It also found evidence of poor education and a lack of standardized language among patients and healthcare practitioners with respect to the legal requirements for informed consent and advance directives (Wahl *et al.*, 2016). That is, while ACP discussions are beneficial to patients, family, and healthcare practitioners, the exact legal effect of different forms of ACP — such as powers of attorney, personal care directives, and goals of care — and their relationship to informed consent are not well understood in clinical practice (Wahl *et al.*, 2016).

### Effectiveness of Instruction Versus Proxy Directives

In a review of 24 published articles, Lewis *et al.* (2016) noted that the assumption that written documentation (e.g., instruction directives) will lead to higher physician confidence or engagement with patients and families could not be objectively demonstrated. Perceived effectiveness of written instruction directives in encouraging end-of-life discussion appears high, but is mostly derived from low-level evidence studies (Lewis *et al.*, 2016).

In contrast to instruction directives, research from the United States demonstrates generally positive outcomes for patients who identified SDMs in proxy directives. Many patients feel more comfortable with a trusted person making decisions on their behalf regarding CPR directions, compared with a reliance on stated wishes (Puchalski *et al.*, 2000). Advance directives that identify an SDM are considered beneficial to healthcare outcomes (Kim, 2014). SDMs provide a direct and responsive link between a healthcare practitioner and the patient, and can speak to the patient's values, beliefs, and wishes not otherwise expressed in an instruction directive. An SDM can consider the consequences of treatment options given an informed understanding of the patient's circumstances; in contrast, an instruction directive may not anticipate the exact circumstances of a treatment decision (Fagerlin & Schneider, 2004).

A study of the use of advance directives in German intensive care units (ICUs) may provide some clarity on the experiences of SDMs and physicians with respect to instruction directives. Leder *et al.* (2015) cite a prevalence of advance directives in Germany that is similar to Canada's (~25%). They reviewed outcomes for 50 ICU patients with advance directives indicated in their electronic medical records. For the majority of cases, follow-up interviews were conducted with a senior physician (n=43), a resident in training (n=46), or a relative (n=19), or all three, or some combination of two. This allowed comparisons between the interview responses of senior physicians and residents in 39 cases, and doctors and relatives in 19 cases. Most advance directives named an SDM (49/50, which included 18 of the 19 relatives interviewed), and all 50 included "validity criteria," that is, specific circumstances in which their instruction directives would become valid. These included circumstances such as serious long-term brain damage (25/50), irreversible unconsciousness (34/50), and inevitable death (37/50).

In their follow-up interviews, Leder *et al.* (2015) noted discordance between how physicians and relatives viewed the instruction directives when asked if they felt valid criteria were met (possible answers were *yes, no, unsure*). Relatives tended to be unsure, while physicians tended to find that validity criteria were not met. Agreement that validity criteria were met occurred in only 4 of 19 cases considered. Part of the issue appears to stem from the ICU physicians interpreting instruction directives as representing a patient's general values and beliefs, and relatives interpreting them as literal directions to follow. Unclear wording in the instruction directive, the responsibility of making a life-or-death decision, and uncertainty about the patient's preference stability helped to explain the higher levels of uncertainty experienced by relatives compared with physicians. Given the aforementioned evidence of poor education and lack of standardized language for advance directives in Ontario (Wahl *et al.*, 2016), it is reasonable to expect similar experiences among SDMs in Canada as in Germany.

### Substitute Decision-Making and Dementia

Substitute decision-making for family carers of people with dementia may be particularly challenging. A systematic review of 16 studies examining 151 hypothetical scenarios posed to 2,595 SDM-patient pairs found that, overall, SDMs were 68% accurate in predicting a patient's self-reported treatment preference (Shalowitz *et al.*, 2006). Prediction accuracy was lowest for treatment preferences in stroke and dementia scenarios (58%) (Shalowitz *et al.*, 2006). In a systematic review of 30 published papers on substitute decision-making by family carers, Lord *et al.* (2015) state:

End of life decisions, including those around resuscitation and artificial nutrition were particularly difficult. Carers often felt excluded from decisions made in hospital and those who felt unsupported by professionals found decision making more difficult. Collaboration with trusted, informed healthcare professionals facilitated the decision-making process for carers as did consulting with other family members in order to seek reassurance following a decision.

In one of the reviewed studies, Sampson *et al.* (2011) found that ACP discussion interventions with carers of hospitalized people with advanced dementia in the United Kingdom increased decisional conflict, as many carers were unwilling to consider hypothesized decisions about future scenarios. However, two other decision-specific intervention studies, one on use of community services in Australia (Stirling *et al.*, 2012) and the other on long-term feeding tube use in a Canadian hospital (Mitchell *et al.*, 2001), found the use of decision aids acceptable and helpful. These studies suggest that the uncertainty in predicting the disease trajectory of a dementia diagnosis adds complexity to decision-making both in instruction directives and for SDMs.

A systematic review analyzing 40 studies on substitute decision-making (32 U.S., 6 Canadian, and 2 European) found that adults who are required to make treatment decisions for others may experience negative emotions such as stress, guilt over their decision, and doubt as to whether they chose correctly (Wendler & Rid, 2011). Fifteen of these studies found that knowledge of the patient's preferred treatment reduced the negative emotional burden for SDMs, and two showed that having an instruction directive substantially reduced the SDM's stress. A caveat, though, was that negative emotions were increased when the treatment that SDMs felt the patient would have wanted did not align with the treatment that was thought to be in the patient's best interests (Wendler & Rid, 2011).

### 5.3.3 Psychiatric Advance Directives

Psychiatric advance directives are “documents that allow users with severe and chronic mental illnesses to notify their treatment preferences for future crisis relapses and appoint a surrogate decision-maker for a period of incompetence” (Nicaise *et al.*, 2013). Few studies have examined the use of these directives; in a systematic review of 38 references to some form of advance directive for mental health, Nicaise *et al.* (2013) identified two studies examining access to and honouring of psychiatric advance directives, and two studies examining outcomes of patients with and without them. A Cochrane Review of the two outcome studies, collectively involving 321 people in England, found some evidence that people who have completed psychiatric advance directives may be less likely to be hospitalized involuntarily, though there was no effect on the overall number of admissions to hospital or contacts with outpatient services (Campbell & Kisley, 2009).

A systematic review of 30 studies on barriers to using psychiatric advance directives identified several, including concerns regarding legal liability, legal provisions to overriding them, and resource implications associated with their implementation (Shields *et al.*, 2014). This review included a paper that considered the use of psychiatric advance directives in Ontario and Quebec (Ambrosini *et al.*, 2008). Ambrosini *et al.* (2008) identified disparate views on the practice among legal professionals, mental health professionals, and community members of review boards for mental health-related consent and capacity issues. These disparities may reflect the differing values, knowledge, or priorities associated with certain professions, and the diversity in provincial mental health legislation. However, Ambrosini and Crocker (2007) note that legal and mental healthcare practitioners see psychiatric advance directives as useful documents to promote patient autonomy, with the caveat that there is a need for greater empirical research on their implementation.

Research on the use and effectiveness of psychiatric advance directives to improve mental healthcare outcomes is lacking in Canada. Given this knowledge gap, it is not possible to speak to the integration of MAID with such directives. Further discussion of MAID and mental disorders can be found in *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*.

### **5.3.4 Evidence from MAID Practice Relevant to ARs for MAID Preference Stability for MAID**

Very little information exists on preference stability for MAID in Canada. Li *et al.* (2017) provide data from the implementation of a hospital-based MAID program in Toronto. The University Health Network reported 74 MAID inquiries between March 8, 2016 and March 8, 2017. Most inquiries (61%) did not proceed to assessment; of those assessed (29 total, 28 of which were already receiving special palliative care), 25 were approved for MAID. Of those approved, 19 received MAID. No patient who retained capacity to consent changed their mind prior to the procedure (Li *et al.*, 2017). Of 379 palliative cancer patients in Canada who completed a survey years prior to the legalization of MAID, 22 (5.8%) expressed a desire for an assisted death at that time (Wilson *et al.*, 2007). About a month later (average 23.7 days), 17 of these patients completed a follow-up interview (the other 5 were unable to be interviewed due to a decline in their condition). Of these 17 patients, 15 persisted in their desire for MAID, one no longer desired MAID, and one changed his mind twice, revoking his desire for MAID and then restating his desire in a subsequent interview (Wilson *et al.*, 2007). Taken together, these limited data suggest preference stability is high for palliative patients desiring MAID.

Under current MAID law in Canada, patients have a number of opportunities to reflect on their decision and change their mind, some explicitly written into the legislation (e.g., assessments by two practitioners are required, along with the 10-day waiting period), and others a function of logistics (e.g., time between scheduled appointments). The University Health Network MAID program follows up a MAID inquiry with discussion between the patient and their most responsible physician, which can include a referral to palliative care, psychiatry, or social work as required, before the inquiry results in the initiation of a MAID assessment (Li *et al.*, 2017). Two assessors must find the patient to be eligible for MAID before the patient can complete a MAID request form and the mandatory 10-day reflection period begins. Thereafter, the MAID team at the hospital reviews all documents, verifies capacity and persistence of the request, and schedules a time and setting for the procedure (Li *et al.*, 2017). Since it is unclear whether the process of writing an AR for MAID would include such periods of reflection or assessment, it is difficult to infer preference stability in ARs for MAID using preference stability of MAID requests in general.

### Recent Opinion Studies on ARs for MAID and Dementia

Recent opinion studies in Quebec have examined the attitudes of informal caregivers (306 respondents out of 471 surveyed) and nurses in geriatrics/gerontology or end-of-life care who had cared for a patient with Alzheimer's or a related disorder (291 respondents out of 541 surveyed) (Bravo *et al.*, 2017a, 2018). The surveys described hypothetical cases and asked participants whether they would support following a patient's AR for MAID in that situation. One case involved a patient diagnosed with Alzheimer's who wrote an AR for MAID and asked for it to be carried out when she could no longer recognize her loved ones. When the patient was described as being at an advanced stage of the disease, living in an LTC facility, unable to make decisions, but still comfortable, 68% of the caregivers and 53% of the nurses supported implementation of the AR for MAID. When the patient was described as in a terminal stage of the disease, showing signs of distress and crying a lot, requiring spoon-feeding, and likely having only a few weeks to live, 91% of caregivers and 83% of nurses supported following the AR for MAID (Bravo *et al.*, 2017a, 2018). Subsequent phases of this study will survey other populations, including physicians, those over age 65, and early-stage Alzheimer's patients (FQAS, 2017). However, evidence from international perspectives suggests there may be marked differences between stated opinion on hypothetical scenarios and actual practice (Section 5.5).

## 5.4 OVERVIEW OF ADVANCE EUTHANASIA DIRECTIVES IN OTHER COUNTRIES

Advance directive provisions are included in the euthanasia laws of Belgium, Colombia, Luxembourg, and the Netherlands, and did not appear to cause contention at the time they were passed. This section provides a brief analysis of how AEDs fit within the legislation on euthanasia in these four countries and, where possible, summarizes how often AEDs are used. It also discusses the types of data available from each country, and explains why nearly all the information on how AEDs are working in practice (Section 5.5) comes from the Netherlands. Finally, it concludes with an analysis of the oversight mechanisms in Belgium and the Netherlands.

### 5.4.1 The Netherlands

In 2002, the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* came into effect in the Netherlands (Gov. of the Netherlands, 2002). Euthanasia had already been accepted and practised in the Netherlands (and somewhat regulated) for decades (Rietjens *et al.*, 2009). The Act allows euthanasia to be provided by a physician whose actions meet the due care criteria as set out in the legislation. The due care criteria, listed in Section 2(1) of the Act (as translated in the 2015 Regional Euthanasia Review Committees *Code of Practice*) state that the physician must:

- a. be satisfied that the patient's request is voluntary and well considered;
- b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
- c. have informed the patient about his situation and prognosis;
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
- e. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
- f. have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

(RTE, 2015c)

The Act includes a provision allowing AEDs. Written advance directives for euthanasia, which apply when people are no longer capable of expressing their will, can be prepared by anyone aged 16 or older. Legally valid advance directives for euthanasia can also be prepared by patients aged 12 to 16, but are subject to additional requirements (RTE, 2015c) (for more details see *The State of Knowledge on Medical Assistance in Dying for Mature Minors*). In the case of AEDs, the due care criteria apply *mutatis mutandis* (to the greatest extent possible), with the directive having the same status as an oral request made by a person with capacity (RTE, 2015c).

The Act contains few details on the actual procedures that patients and physicians should follow when dealing with a euthanasia request. It consists mainly of the six due care criteria and rules for the establishment, duties, and reporting responsibilities of the Regional Euthanasia Review Committees (RTE). Thus, based on its review of thousands of euthanasia cases, the Dutch RTE published the *Code of Practice* to help patients and physicians deal with euthanasia requests in a manner that complies with the Act (RTE, 2015c). The *Code of Practice* was updated in 2018 though, as of September 2018, the updated version was only available in Dutch (RTE, 2018a).

The *Code of Practice* clarifies the role of the independent consulting physician in assessing a euthanasia request. It states that the physician performing the euthanasia procedure “must take the independent physician’s opinion very seriously, but he does not need the independent physician’s ‘permission’ to carry out euthanasia” (RTE 2015c). If the two do not agree, the physician may still decide to grant the patient’s request, but must be prepared to offer an explanation to the RTE (RTE, 2015c).

### Applying the Due Care Criteria to AEDs

One key aspect of the *Code of Practice* that affects AEDs is the point that euthanasia can only be performed when the patient retains some level of consciousness. The due care criteria require the physician to confirm that a patient is suffering. According to the *Code of Practice*, “suffering assumes a conscious state. If a patient is in a coma, i.e. a state of complete unconsciousness, he is unable to experience suffering” (RTE, 2015c). Thus, if the patient falls into a coma just before the euthanasia procedure, the physician may not carry out the procedure. However, if the patient is in a state of reduced consciousness but still shows signs of suffering, or if the coma or reduced consciousness was induced by medication, the physician may proceed. The same rules apply to AEDs: they may only be followed for patients with reduced consciousness if

signs of suffering are evident (RTE, 2015c). This is in direct contrast to the laws in Belgium and Luxembourg, where patients *must* be unconscious for AEDs to be followed (Sections 5.4.2 and 5.4.3).

The *Code of Practice* provides guidance on how to meet certain due care criteria for AEDs. To conclude that the patient's request is voluntary and well considered (requirement (a)), the physician should consider previous communication with the patient and conversations with the patient's family or representative. For requirement (b), it is up to the physician to establish that the patient is suffering unbearably immediately prior to euthanasia. To satisfy requirement (c), the physician must be confident that the patient was informed of their diagnosis when oral communication was still possible. Requirement (d) (no reasonable alternative) is a conclusion that is ideally made by the physician and patient together. Because this is not possible with an incapacitated patient, the physician must consult the AED, consider what the patient said when they could still communicate, and determine whether the patient's views apply to the current situation. The independent consulting physician (requirement (e)) must visit the patient but will likely not be able to engage in clear conversation; thus, the consulting physician will need to rely on their own observations, patient records, the AED, and conversations with the attending physician and family. For these adjustments to be made successfully, the patient's physician must keep thorough records. The attending and consulting physicians must also be able to interpret the patient's behaviour and verbal cues to conclude that they still desire euthanasia and the AED must clearly indicate what the patient considers to be unbearable suffering and the conditions under which euthanasia should be performed (RTE, 2015c).

### Use of AEDs

As of 2005, an estimated 7% of adults aged 20 or older in the Netherlands had an AED (van Wijmen *et al.*, 2010). Physicians are not obliged by law to comply with AEDs (though they are obliged to comply with advance directives to forego treatment) (de Boer *et al.*, 2011). In contrast to the euthanasia oversight body in Belgium (Section 5.4.2), the RTE in the Netherlands does not report the annual number of assisted deaths that occur based on an AED. However, as discussed further in Section 5.5.2, studies have shown that compliance with AEDs for people with dementia is quite low (Rurup *et al.*, 2005; de Boer *et al.*, 2010a; de Boer *et al.*, 2011).

### 5.4.2 Belgium

Euthanasia was legalized in Belgium with *The Belgian Act on Euthanasia of May 28<sup>th</sup>, 2002*. The 2002 version of the Act states that physicians who carry out euthanasia are not committing a crime, provided they ensure that:

- the patient has attained the age of majority or is an emancipated minor, and is legally competent and conscious at the moment of making the request;
- the request is voluntary, well-considered and repeated, and is not the result of any external pressure;
- the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident.

(Gov. of Belgium, 2002)

In 2014, the Act was amended to allow euthanasia for all minors with the capacity for discernment, regardless of their age, provided they meet the other eligibility criteria (Gov. of Belgium, 2002).

Before the law was passed, euthanasia was “treated as intentionally causing death under criminal law,” but prosecutions were rare (Deliens *et al.*, 2000). Public acceptance of euthanasia was high in Belgium prior to the passing of the Act, having grown sharply in the last 20 years of the 20<sup>th</sup> century (Cohen *et al.*, 2006).

### Stipulations for AEDs

In cases where a patient cannot express their will, an advance directive consenting to physician-assisted euthanasia is permitted, provided the directive was written while the person was legally competent and the physician ensures that:

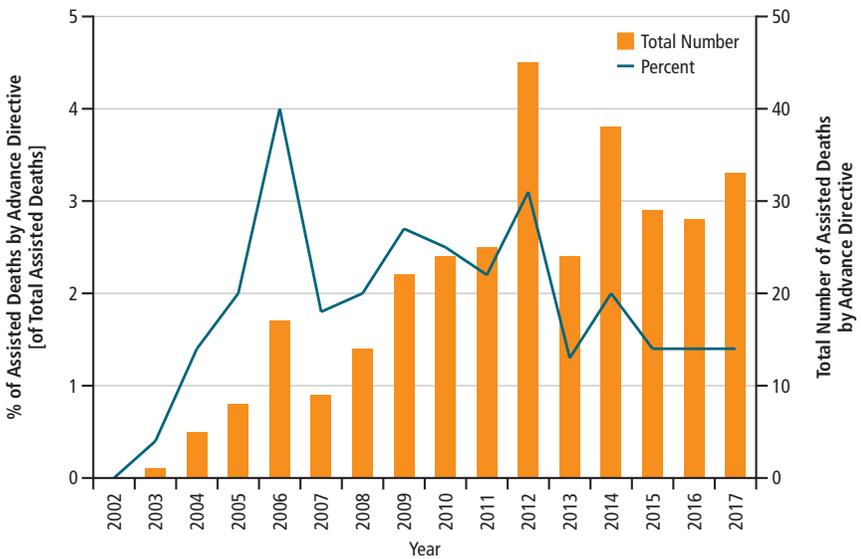
- the patient suffers from a serious and incurable disorder, caused by illness or accident;
- the patient is no longer conscious;
- this condition is irreversible given the current state of medical science.

(Gov. of Belgium, 2002)

An individual may designate in their AED one or more person(s) taken into confidence who inform(s) the attending physician about the patient’s advance directive (Gov. of Belgium, 2002). Before euthanasia is carried out based on an AED, the case must be discussed with an independent consulting physician, the patient’s nursing team (if one exists), the person taken into confidence (if one has been designated), and any relatives of the patient chosen by the person taken into confidence. In addition, the report of the consulting physician must be shared with the person taken into confidence. Belgian AEDs are only valid for five years after their drafting (Gov. of Belgium, 2002).

### Use of AEDs

Similar to the Netherlands, there was little discussion of the advance directive provision in the Belgian euthanasia law at the time of its passage. Unlike the Netherlands, however, the advance directive provision does not seem to have raised much controversy in the years since euthanasia was legalized. This may be because AEDs can only be used in Belgium if a patient is irreversibly unconscious (Gov. of Belgium, 2002), and therefore do not apply to dementia cases where capacity is lost but consciousness remains. According to Nys (2017), “there is a consensus in Belgium that ‘irreversibly unconscious’ has a very limited meaning and is synonymous to the so-called persistent vegetative state.” From 2002 to 2017, there were 322 assisted deaths due to an AED in Belgium, representing between 1% and 4% of all assisted deaths (Figure 5.1).



Data Source: CFCEE, 2004, 2006, 2008, 2010, 2012, 2014, 2016, 2018

Figure 5.1

#### Assisted Deaths Resulting from an Advance Euthanasia Directive in Belgium, 2002–2017

Data include all euthanasia cases reported to the Belgian Federal Control and Evaluation Commission on Euthanasia (CFCEE) from 2002 to 2017. Right y-axis (orange bars) shows the total number of assisted deaths resulting from an AED. Left y-axis (blue line) shows the percentage of assisted deaths resulting from an AED (out of all assisted deaths).

Although Belgian law prohibits euthanasia based on AEDs for conscious patients who lack decision-making capacity, patients with dementia are eligible for euthanasia as long as they are decisionally capable (Montero, 2017). From 2002 to 2013, 62 patients with dementia received euthanasia in Belgium; however, it is unclear whether the dementia itself, or another medical condition, prompted their euthanasia requests (Dierickx *et al.*, 2017).

### 5.4.3 Luxembourg

Luxembourg modelled its euthanasia law largely on that of Belgium, and the criteria related to advance directives are the same (Gov. of Luxembourg, 2009; Nys, 2017). Therefore, in Luxembourg, AEDs are valid only in the case of irreversible unconsciousness (CNCE, 2011). There was no identifiable public debate on the AED provision within the *Act of 16 March 2009 on Euthanasia and Assisted Suicide* and only one death following an AED has been reported in Luxembourg (in 2012), out of 52 assisted deaths from 2009 to 2016 (CNCE, 2017).

### 5.4.4 Colombia

Colombia legalized euthanasia in 2015 under the Colombian Ministry of Health and Social Protection's *Resolution Number 00001216* on the right to die with dignity (Gov. of Colombia, 2015). Although Colombia's Constitutional Court ruled in 1997 that euthanasia was not a crime under certain circumstances (the patient provides free and informed consent, the procedure is done by a physician, and the patient has a terminal disease that causes suffering), it was not clearly legal (Ceaser, 2008). The development of formal provisions to allow the practice of euthanasia occurred because of a Constitutional Court judgment in 2014 (Constitutional Court of Colombia, 2014).

According to the resolution, a patient of legal age can request a physician-assisted death provided they have a terminal disease, defined as:

a serious disease or pathological condition, diagnosed by an expert physician, in clear and irreversible progression and has a prognosis of imminent or short-term death, with no possibility of undergoing a curative treatment of proven efficiency which can change the imminent death prognosis, or when the treatment used to cure the disease is no longer efficient.<sup>6</sup>

(Gov. of Colombia, 2015)

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6 Unofficial translation.

For the request to be granted, “the patient’s consent shall be free, informed and unmistakable.” The resolution further states: “Advance directives or living wills, for this particular case, are considered valid expressions of consent and shall be respected as such” (Gov. of Colombia, 2015). When an advance directive exists, a patient’s surrogate can make the request for euthanasia on a patient’s behalf. Despite the presence of an advance directive, the surrogate can also “withdraw this request and choose other alternatives” (Gov. of Colombia, 2015). In all cases, a patient’s request must be approved by a committee consisting of a physician specialized in the pathology of the patient (this cannot be the patient’s treating physician), a lawyer, and a clinical psychologist or psychiatrist (Gov. of Colombia, 2015).

At this time, no statistics on physician-assisted death in Colombia have been identified. Only one Colombian physician has spoken publicly about performing euthanasia. He has euthanized unconscious patients, and in these cases he “asks the family whether the person had expressed desires not to be kept alive after all hope for recovery was gone” (Ceaser, 2008). Colombia does not place any restrictions on the use of AEDs based on the consciousness level of the patient.

#### **5.4.5 Summary of Laws and Guidelines for AEDs in Countries that Allow Them**

The laws (and guidelines in the Netherlands) that allow for AEDs contain a range of stipulations to ensure that consent is given and vulnerable people are protected; these are summarized in Table 5.2.

Table 5.2

**Stipulations for Advance Euthanasia Directives in Belgium, Colombia, Luxembourg, and the Netherlands**

Stipulation	Country				
	Belgium	Colombia	Luxembourg	The Netherlands	
	Required by Law	Required by Law	Required by Law	Required by Law	Suggested by RTE
AED must be in writing	X	X	X	X	
AED must be written by the person requesting euthanasia and cannot result from a proxy request	X	X	X	X	
AED must be witnessed	X		X		
AED must be discussed with a physician when it is drafted or updated					X
AED must be retained in the patient's medical record	X		X		X
AED must be registered in a national registry	X*		X		
Patient's case must be assessed by independent consulting physician(s)	X	X	X	X	
AED must be discussed with the patient's designated representative and/or family members	X	X	X		X
AEDs are valid for five years after they are signed	X		X		
AEDs may only be followed for irreversibly unconscious patients	X		X		
AEDs may only be followed for patients with some level of consciousness					X**
Euthanasia requests must be evaluated by an oversight committee		X			
Euthanasia deaths must be reported to an oversight committee	X	X	X	X	
Statistical data and information on implementation are regularly reviewed and reported publicly (annually or biannually)	X		X	X	

Source: Gov. of Belgium, 2002; Gov. of the Netherlands, 2002; Gov. of Luxembourg, 2009; CNCE, 2011; Gov. of Colombia, 2015; RTE, 2015c

**Notes for Table 5.2**

\* Only AEDs that are prepared using a model contained within the annex to the Royal Decree of April 3 2003 “can be registered by the local authorities of the place where the person concerned has drafted a directive. These authorities are obliged to register the directive and transmit it to a database kept at the Ministry of Health” (Nys, 2017). Patients are not required to use this model to prepare their AED (Nys, 2017).

\*\* The Dutch euthanasia law does not specifically state that AEDs only apply to conscious patients. However, the due care criteria do state that the physician must be satisfied that the patient’s suffering is unbearable. The RTE Code of Practice clarifies that a patient who is completely unconscious cannot suffer, and is therefore not eligible for euthanasia (RTE, 2015c).

**5.4.6 Data Availability in Countries that Allow AEDs**

Countries that allow AEDs require that assisted deaths be reported to an oversight body created and regulated through legislation (Table 5.2). In Belgium, this body is the Federal Control and Evaluation Commission on Euthanasia (CFCEE) (Gov. of Belgium, 2002); in Luxembourg, the National Commission of Control and Evaluation (CNCE) (Gov. of Luxembourg, 2009); and in the Netherlands, the Regional Euthanasia Review Committees (RTE) (Gov. of the Netherlands, 2002). In Colombia, an Interdisciplinary Scientific Committee for the Right to Die with Dignity evaluates a euthanasia request *before* implementation, and then sends a record of the procedure to the government’s Ministry of Health and Social Protection (Gov. of Colombia, 2015).

These oversight bodies, with the exception of Colombia, produce summary documents of reported cases. The CNCE has produced four biannual reports (CNCE, 2011, 2013, 2015, 2017); however, since 2009, only one patient (in 2012) has received euthanasia based on the instructions in an AED in Luxembourg. Thus, Belgium and the Netherlands are the only two countries with any substantial practical experience with AEDs.

Since 2003, the RTE in the Netherlands has published an annual report on their work “reviewing notifications of termination of life on request and assisted suicide on the basis of due care criteria” (RTE, 2017d). The reports also give physicians and other interested parties insight into specific cases, such as those that are important for developing clinical practice and those that have generated public interest (e.g., cases involving psychiatric disorders and dementia). Annual reports include detailed case summaries and refer readers to the RTE website for the full text of each case (e.g., RTE, 2016c). In addition, there have been three large-scale, publicly available evaluations of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*, published in 2005, 2011, and 2017. The CFCEE in Belgium publishes biannual reports, which do not include case descriptions. It is difficult for the public to assess the functioning of the CFCEE, since its reports do not contain information about specific cases, nor do they provide feedback to the medical profession (Lewy, 2011).

In addition to the RTE annual reports and case summaries, Dutch data on implementing AEDs can be found in academic research papers, media, and narrative reports. Less information on AED implementation exists in Belgium, in part because AEDs are valid only when patients are irreversibly unconscious. Respecting AEDs for irreversibly unconscious patients appears less controversial than respecting them for conscious patients who lack decision-making capacity, likely because living in a persistent vegetative state offers no value to the patient (Menzel & Steinbock, 2013). When permanently unconscious, the patient has no current preferences that could conflict with those expressed in an AED (Menzel & Steinbock, 2013). Therefore, debate and discussion of AEDs in Belgium have not centred on implementation, but rather on amending the law to allow AEDs for patients who are still conscious, but lack decision-making capacity. Calls for extending the Belgian law on AEDs have been made in several parliamentary bills (Montero, 2017). Most of the literature in Belgium related to AEDs is limited to regulatory debate and ethical discussion. Furthermore, as of 2017, no research results describing public opinion in Belgium on euthanasia for patients with advanced dementia have been reported (Gastmans, 2017).

#### 5.4.7 Oversight Mechanisms in Belgium and the Netherlands

In Belgium and the Netherlands, where most of the high-profile euthanasia cases have occurred, there is ongoing debate about the transparency and efficacy of the bodies that monitor the practice. This sub-section summarizes the review processes in these two countries and discusses some of the controversial aspects.

##### Summary of the Review Process

The review processes in both Belgium and the Netherlands rely on physicians to report their own euthanasia practices (Lemmens, 2018). In the Netherlands, the RTE reviews the actions of the reporting physician, based on the physician's self-report and the report of the consulting physician, to determine whether they followed the due care criteria. The RTE may request more information if needed, from the reporting physician, consulting physician, pathologist, or those who cared for the patient (Gov. of the Netherlands, 2002). If the physician violated substantive due care criteria, the case is handed over to the Public Prosecution Service and the Healthcare Inspectorate (Onwuteaka-Philipsen *et al.*, 2017).

In Belgium, the CFCEE first evaluates an anonymous part of the physician's report that contains details about the case (Gov. of Belgium, 2002). If this anonymous section raises any doubt about whether the nature of the patient's case and the physician's actions follow the law, the CFCEE can open an additional section of the report containing the identity of the patient, the physician who performed the euthanasia procedure, the consulting physicians, the pharmacist, and any

other people consulted. The CFCEE can then also contact the physician to request the full medical records for the case. As in the Netherlands, the case can be given to the Crown prosecutor, but only if a two-thirds majority of the CFCEE agrees that the physician did not act in accordance with the law (Gov. of Belgium, 2002).

### Issues with Transparency

The RTE believes that they have an educational role in improving the exercise of due care by physicians through provision of feedback and publication of cases (Onwuteaka-Philipsen *et al.*, 2017). Even if they determine that a physician has followed due care, they may still include comments in their decision to improve the physician's future conduct; if they require more information, they may speak with the physician or schedule an in-person meeting (Onwuteaka-Philipsen *et al.*, 2017). Many of the RTE decisions about complex euthanasia cases are publicly available. The Working Group took advantage of these available cases and completed a comparative analysis (Section 5.6). The researchers who carried out the third evaluation of the Dutch euthanasia law remarked on the openness and flexibility of the RTE during the process; members of the RTE filled out questionnaires, participated in interviews or group discussions, allowed researchers to attend their meetings, and provided access to a database of all reported euthanasia cases from 2002 to 2015 (Onwuteaka-Philipsen *et al.*, 2017).

The CFCEE in Belgium provides less feedback to physicians; they may never know a physician's identity unless they have further questions about a case. Thus, in contrast to physicians in the Netherlands, those in Belgium do not receive a reasoned opinion on their euthanasia case (den Hartogh, 2017). The Belgian review system has been described as a "fairly impenetrable black box,"<sup>7</sup> which limits the learning opportunities it can provide (den Hartogh, 2017). Commentaries in the annual reports about challenging cases provide only short excerpts from case reports and limited critical analysis (Lemmens, 2018).

Despite a more transparent review process in the Netherlands than in Belgium, omissions in the RTE reports have been identified. One omission, discussed by Chabot (2017), concerns the reporting of procedural details when a patient with advanced dementia receives euthanasia (e.g., Case 2016-85; Section 4.3.7). Chabot (2017) quotes a passage in the third evaluation of the Dutch euthanasia law, which states that covert administration of a drug "can in those cases be inherent to the nature of the situation and has not previously been identified as a problem by the RTEs"<sup>8</sup> (Onwuteaka-Philipsen *et al.*, 2017). This suggests

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7 Unofficial translation.

8 Unofficial translation.

that Case 2016-85 was not the first occurrence of surreptitious drug delivery, but it was the first time that the RTE publicly reported it. Indeed, a similar event occurred in 2012 when the spouse of a woman with dementia mixed sleep medication into her porridge before the physician arrived to perform euthanasia (Chabot, 2017). Chabot (2017) asserts that this did not align with the RTE's usual procedure, which involves determining what drugs were used and judging any deviations from the standard of practice as careless.

### Issues with the Method of Reporting and Quality of the Review Process

Euthanasia review processes rely on self-reporting by the physician. This has the potential to lead to two issues. First, physicians may fail to submit a report. Based on a study of death certificates from 2007 in Flanders, Belgium, and a questionnaire distributed to the treating physician for each deceased person, approximately half of all estimated euthanasia cases were reported to the CFCEE (Smets *et al.*, 2010). A similar study conducted as part of the third evaluation of the Dutch law using death certificates estimated a reporting rate of 82%, virtually identical to rates previously reported in 2005 and 2010 (Onwuteaka-Philipsen *et al.*, 2017). The most common reason for non-reporting was that the physician did not think they had performed an act of euthanasia (van der Heide *et al.*, 2007; Smets *et al.*, 2010). Most cases involving drugs with uncertain lethal effects (e.g., opioids) were unlikely to be reported as cases of euthanasia (van der Heide *et al.*, 2007; Smets *et al.*, 2010). The second issue with self-reporting is that physicians decide how to present their cases and what to include as relevant. Physicians are aware of potential consequences of transgressions; an argument has been made that training physicians in improving their reports may also make them more aware of the elements they must provide to avoid a judgment of 'due care criteria not complied with' (Lemmens, 2018).

In an analysis of 32 Dutch euthanasia cases from 2012 to 2016 that did not meet due care criteria, Miller and Kim (2017) found that most of these cases (69%) involved a failure to meet only procedural criteria (e.g., lack of independence of the consulting physician or incorrect route, dose, or order of drug administration). In contrast, only 31% of the cases did not meet at least one substantive criterion (e.g., lack of a voluntary and well-considered request or doubts about the unbearable nature of suffering). Even when substantive criteria were cause for a judgment of non-compliance, Miller and Kim (2017) note that the RTE focused on the process the physician followed, rather than the physician's judgment in the case. According to Miller and Kim (2017), "the criteria are designed and applied to evaluate the procedures doctors follow (taking 'due care') and not to directly assess the actual eligibility of the patients; they appear designed to determine 'was the doctor careful?' more than 'was

EAS [euthanasia and physician-assisted suicide] appropriate in that case?” This suggests that caution should be applied in interpreting the judgments expressed by the RTE in case reports. Even if the RTE determine that due care criteria are met, this does not necessarily signify a lack of doubt and uncertainty. Of relevance to ARs for MAID, several cases that violated substantive elements of due care involved non-terminally ill patients, and most included controversial features such as mental disorders or patients who lacked decisional capacity. For incapacitated patients, it was complicated to determine whether the due care criteria, such as the presence of unbearable suffering, were met (Miller & Kim, 2017).

### Issues with Follow-Through for Judgments of Non-Compliance

Since 2002, the CFCEE in Belgium has found one case of a physician whose actions did not meet the requirements of the law (den Hartogh, 2017). Thus, it is not possible to comment on the level of follow-through from such a judgment. In his resignation letter from the CFCEE, made available online by the Associated Press (Vanopdenbosch, n.d.), a former member revealed that, in September 2017, controversy erupted within the CFCEE when a minority of its members blocked the referral for prosecution of a case where a physician allegedly provided euthanasia to a patient without consent (Lemmens, 2018). The patient had severe dementia and Parkinson’s disease, lacked the mental capacity to request euthanasia, and had no AED. The two co-chairs of the CFCEE asserted that the physician was mistaken in characterizing the case as euthanasia, as it was actually a case of palliative sedation (Cheng, 2018).

In the Netherlands, between 2002 and 2017, the actions of 101 physicians were found to have not complied with due care criteria (RTE, 2003, 2004, 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012b, 2013, 2014a, 2015d, 2016c, 2017d, 2018b). As den Hartogh (2017) notes, most cases involved procedural or technical reasons for the judgment of non-compliance. As of March 2018, the Public Prosecution Service was investigating five cases of euthanasia, including case 2016-85 (Section 4.3.7), a case involving a woman with Alzheimer’s disease, and a case involving a woman with terminal cancer given euthanasia while in a coma; no charges have yet been laid in any case (DutchNews, 2018). To assess whether a case warrants criminal prosecution, the Public Prosecution Service conducts its own investigation. Although it is not expected that every case it flags will result in prosecution, 17% of surveyed members of the RTE (6 of 36) indicated that they found their work less meaningful because the Public Prosecution Service has never decided to bring charges (Onwuteaka-Philipsen *et al.*, 2017).

### Issues with Overburdened Review Committees

The number of assisted deaths in both Belgium and the Netherlands has risen steadily since the laws were enacted in 2002. Belgium reported 235 assisted deaths in 2003 (CFCEE, 2004) and 2,309 in 2017 (CFCEE, 2018). The Netherlands reported 1,882 in 2002 (RTE, 2003) and 6,585 in 2017 (RTE, 2018b). Some have questioned whether the Belgian and Dutch oversight bodies are able to thoroughly review this many cases each year (Lemmens, 2018). The CFCEE in Belgium, consisting of 16 members with expertise in medicine and law, meets 11 times per year; thus, its assessment of the 2015 cases required a review of more than 150 reports at each meeting (Lemmens, 2018).

In the Netherlands, there are five regional committees, each consisting of a legal specialist (who also serves as the chair), an ethicist, a physician, deputy members, a secretary, and one or more deputy secretaries (Gov. of the Netherlands, 2002). In their third evaluation of the Dutch euthanasia law, Onwuteaka-Philipsen *et al.* (2017) asked some members of the RTE whether, given the increasing number of cases each year, they thought the current review system was sustainable. Of 38 interviewees, 63% felt that it was sustainable and 37% felt that it was not. In general, members felt that the workload was high, citing various reasons such as additional tasks outside of their core assessment work, reports with greater complexity, and an increased number of reports without a corresponding increase in the number of committee members (Onwuteaka-Philipsen *et al.*, 2017).

## 5.5 ADVANCE EUTHANASIA DIRECTIVES: HOW ARE THEY WORKING IN PRACTICE?

Nearly all of the information about implementation of AEDs discussed in this section is from the Netherlands. The reasons for this, articulated above, are the lack of implementation experience in Colombia and Luxembourg, and the lack of detailed data (from either the review commission or academic studies on AEDs) in Belgium. Several caveats exist in the application of Dutch data to the Canadian context. Canada's low population density compared with the Netherlands might make delivery of MAID more difficult; more people die in hospital in Canada than in the Netherlands and it is less common in Canada than in the Netherlands for patients to have long-standing relationships with their physicians (Sibbald, 2016). However, the use of specialized end-of-life clinics is increasing in the Netherlands and patients who use them may not have had a long relationship with the physician who provides them with euthanasia; physicians connected to an end-of-life clinic reported 13% of euthanasia cases in 2017, while a general practitioner reported 85% (RTE, 2018b).

For AEDs specifically, one important difference between Canada and the Netherlands must be underscored. Dutch legislation was initiated by physicians, to provide legal protection to physicians who were already practicing euthanasia, rather than arising from a court case as it did in Canada (Sibbald, 2016). In the Netherlands, the physician must be convinced that the patient's suffering is unbearable; Canadian law stipulates that it is the patient who determines whether their condition "causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable" (GC, 2016). Canada's MAID law does not discuss situations in which a healthcare practitioner evaluates the eligibility of patients who lack decision-making capacity, which may include patients who cannot express whether they are experiencing suffering. In the Netherlands, the physician must be convinced that the patient's suffering is unbearable, and the physician is the authority in deciding whether euthanasia is an appropriate response. It is unclear in the Canadian context what the role of the healthcare practitioner would be in interpreting a patient's suffering were an AR for MAID to be involved.

This section begins by discussing some of the issues that have arisen when dealing with AEDs in the Netherlands. The focus is on advanced dementia patients whose cases have generated vigorous debate for decades (e.g., Hertogh *et al.*, 2007). It concludes with an analysis of 16 Dutch euthanasia cases involving decisionally incapacitated patients with AEDs.

### **5.5.1 Attitudes Towards Euthanasia in Advanced Dementia Conflict with Actual Practice**

De Boer *et al.* (2010b) note that different pictures may emerge depending on whether researchers are investigating attitudes and opinions towards euthanasia or the actual practice of euthanasia. Studies indicate that different groups express different levels of support for AEDs in dementia patients who lack capacity; the general public and relatives of dementia patients are more permissive in their views than both nurses and physicians, with physicians being the most restrictive (Rurup *et al.*, 2006; Kouwenhoven *et al.*, 2013; Tomlinson & Stott, 2015). The authors of these studies hypothesized that this could be due to the different responsibilities of each group. Physicians actually have to carry out a patient's request, and when a patient cannot consent, this act comes with a heavy emotional burden. In a random sample of 2,500 Dutch physicians with 1,456 respondents, elderly care physicians (n=287) were less likely than general practitioners (n=708) and clinical specialists (e.g., cardiologists, surgeons, neurologists, n=461) to find it conceivable that they would perform euthanasia in the case of advanced dementia (Bolt *et al.*, 2015). The authors theorized that the reluctance of elderly care physicians "could be due to their experience with and knowledge about the complexity of this specific situation" (Bolt *et al.*, 2015).

Regardless of the different views among physicians and relatives, both are more positive about respecting AEDs in principle than in practice. Relatives of patients with dementia generally support euthanasia if an AED exists (Rurup *et al.*, 2006), but when they are faced with the decision to follow an AED, most decide against it (Rurup *et al.*, 2005; de Boer *et al.*, 2011). In one study, 63% of relatives of nursing home residents with dementia asked physicians not to comply with the residents' AEDs, but instead to forego life-sustaining treatment (de Boer *et al.*, 2011). An earlier study found that 73% of relatives of nursing home residents with dementia made the same request (Rurup *et al.*, 2005). Some of the reasons given by relatives were that they were not ready for euthanasia, they did not feel that the patient was suffering, and they could not ask for euthanasia when their loved one still had enjoyable moments (de Boer *et al.*, 2011). Stopping treatment appeared to be an acceptable alternative that was easier for relatives to choose than requesting active euthanasia; the AED was viewed as support for a decision to forego treatment (de Boer *et al.*, 2011). Working Group members note that this may highlight how people in the Netherlands perceive actively ending a person's life as distinct from other end-of-life practices.

### **5.5.2 Dutch Physicians Are Reluctant to Follow AEDs in Advanced Dementia Patients**

A 2007 to 2008 survey of 434 Dutch elderly care physicians revealed that, while 110 indicated that they had treated a patient with dementia who had an AED, only 3 physicians had actually performed euthanasia in such a case (1 physician assisted 3 individuals, for a total of 5 patients) (de Boer *et al.*, 2010a; de Boer *et al.*, 2011). The top reason given for lack of compliance with an AED, cited by 51% of respondents, was that in the physician's opinion the patient experienced "no unbearable suffering" or "no hopeless suffering" (de Boer *et al.*, 2011). More than half (54%) of elderly care physicians felt that they were forced to decide this for themselves because they believed that it was "impossible to determine whether an incompetent person experiences his/her 'dementia' as unbearable and hopeless suffering" (de Boer *et al.*, 2010a). Most (76%) also felt that it was "impossible to determine at what moment an advance directive for euthanasia of a person with dementia is to be carried out" (de Boer *et al.*, 2010a). All patients with dementia who received euthanasia shared an important characteristic: they were "deemed competent and able to communicate their wishes" (de Boer *et al.*, 2010a). Indeed, RTE annual reports from 2002 to 2017 indicate that all or most of the patients who received euthanasia due to suffering caused by dementia were in the initial stages of the disorder and still had decisional capacity.

Based on their study, de Boer *et al.* (2010a) identified a crucial element underpinning the reluctance of physicians to carry out AEDs in patients with dementia — the impossibility of meaningful patient–physician communication. An AED replaces an oral request for euthanasia, the first due care criterion, but, without communication, it is difficult to fulfil some of the other criteria. Onwuteaka-Philipsen *et al.* (2017) discussed assertions made by den Hartogh (2015, available in Dutch only) on this issue. Den Hartogh believes that requirement (c), which states that the physician must have informed the patient about his/her situation and prognosis, is void in the case of an AED and that requirement (d), which states that the physician and patient must conclude together that there is no reasonable alternative, now relies completely on the physician’s assessment (den Hartogh, 2015). The RTE *Code of Practice* does not dispute these opinions, but takes the view that requirements (c) and (d) can still be fulfilled based on previous communication with the patient when they still had capacity and by inferring whether the patient’s previously expressed views apply to the current situation, respectively (RTE, 2015c).

Even though the RTE have endorsed euthanasia on the basis of an AED in the context of dementia, resistance has developed in the Netherlands with respect to the practice. This is highlighted by the fact that more than 460 physicians — including many geriatricians, SCEN consultants,<sup>9</sup> and psychiatrists — signed a public letter ([www.nietstiekembijdementie.nl](http://www.nietstiekembijdementie.nl)) committing to never “provide a deadly injection to a person with advanced dementia on the basis of an advance request” (as translated in Lemmens, 2018). One member of the RTE resigned because of her perception that the RTE has become more permissive of euthanasia for people with severe dementia (Lemmens, 2018).

De Boer *et al.* (2010a) conclude that the very situations for which AEDs were developed (i.e., when patients can no longer communicate their wishes) are also the situations in which they are not being followed. Research from in-depth interviews performed as part of a larger study on opinions of end-of-life care in the Netherlands came to the same conclusion: most physicians feel they must be able to communicate personally with a patient to assess the character of their suffering and the voluntariness of their request (Kouwenhoven *et al.*, 2015). Only then will they “experience a moral appeal that is strong enough to be willing to perform euthanasia” (Kouwenhoven *et al.*, 2015).

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9 See Section 6.2.5 for more information on the Support and Consultation on Euthanasia in The Netherlands (SCEN) project.

One of the reasons that physicians must experience an intense moral appeal before they agree to carry out a euthanasia request is the emotional burden that comes with performing such an act. There are no studies addressing the feelings of physicians who have provided euthanasia based on AEDs. Qualitative studies on euthanasia experiences in general suggest that although most physicians found the overall process satisfying and positive, some were nervous because they felt pressure to succeed or were worried about the reactions of family members (van Marwijk *et al.*, 2007). Many described feelings of loss and loneliness, and a need for personal support (van Marwijk *et al.*, 2007; Dees *et al.*, 2013). In the case of decisionally incapacitated patients who cannot be asked if they are suffering unbearably, or if (and when) they would like to be euthanized, even more responsibility is placed on physicians (de Boer *et al.*, 2010a).

### 5.5.3 AEDs Are Often Prepared Without Assistance

In the Netherlands, an AED does not have to be drawn up with a physician (Gov. of the Netherlands, 2002). Anyone may become a member of the Dutch Society for a Voluntary End of Life ([www.nvve.nl](http://www.nvve.nl)), which provides access to pre-made forms that can be filled out to convey one's wishes, though such forms are not mandatory. Indeed, the RTE *Code of Practice* states that an AED drafted in the patient's own words "will generally be regarded as more significant than a pre-printed, standard form" (RTE, 2015c). The *Code of Practice* also clarifies that it is the patient's responsibility to discuss their AED with their physician when drafting or updating it (RTE, 2015c). Though law does not mandate discussion of an AED with a physician, the judgments of the RTE in various individual cases indicate the value of such discussions (Section 5.6).

A Dutch study by Vezzoni (2005) indicated that patients often draft advance directives alone. This study surveyed family doctors and revealed that approximately 75% of patients with advance directives had drafted them alone; of those that were drafted alone, 71% included a request for euthanasia. The author hypothesized that lack of physician involvement could be part of the reason why physicians consider advance directives to be of low medical quality (Vezzoni, 2005).

According to family doctors in the Netherlands, what most increases the effectiveness of an advance directive is "clear formulation of conditions of applicability" (Vezzoni, 2005). Approximately half (49%) of these same family doctors stated that those conditions of applicability are often or always expressed in generic terms; more than half of Dutch nursing home doctors surveyed (57%) also noted the frequent use of generic terms in directives (Vezzoni, 2005).

### 5.5.4 Institutions in Belgium and the Netherlands Are Imposing Extra Conditions Not Required by Euthanasia Legislation

In principle, the 2002 Dutch euthanasia law allows AEDs to be followed for patients even if they no longer have the capacity to make a voluntary and well-considered request for euthanasia (de Boer *et al.*, 2010b). Despite this, many nursing homes in the Netherlands have policies stating that AEDs will not be complied with in cases of dementia (de Boer *et al.*, 2011). These policies are relevant, since approximately 90% of patients with dementia in the Netherlands die in nursing homes, where elderly care physicians look after them (Houttekier *et al.*, 2010). In a sample of 405 elderly care physicians, de Boer *et al.* (2010a) found that almost half (188 or 46%) worked in nursing homes with specific policies on euthanasia and dementia. Of these 188 physicians, most (63%) indicated that AEDs are not followed per se, but are taken into account when making treatment decisions; a further 16% of physicians stated that they are not followed at all (de Boer *et al.*, 2010a).

A study analyzing the policies of 345 of the 594 nursing homes in Flanders, Belgium (where AEDs are only valid in irreversibly unconscious patients) revealed that 37.7% had institutional ACP guidelines mentioning euthanasia (De Gendt *et al.*, 2010). Policies in 6.2% of nursing homes did not permit euthanasia in the context of ACP, and policies in 13.1% allowed it according to Belgium's legal criteria as well as additional institutional criteria. The remaining 18.4% allowed it according to the legal criteria alone (De Gendt *et al.*, 2010).

The members of the Belgian Advisory Committee on Bioethics considered the issue of whether a care facility should be permitted to prohibit euthanasia on its premises or whether it should be able to add eligibility criteria not in the law (Belgian Advisory Committee on Bioethics, 2014). The committee could not reach consensus on this matter. Some members thought that it was neither "legal nor ethically legitimate" for an institution to enforce additional criteria and stated that inconsistently responding to patient requests could lead to inequality of access. They felt that while certain criteria (e.g., requiring patients who request euthanasia to be examined by a palliative care team) could be presented as precautionary measures, they were actually excessive hindrances. In contrast, other members thought that institutional policies were acceptable if they were meant to generate a "high-quality medical response to the patient's request," arguing that the law could not compel any entity to administer or arrange for euthanasia. These members stated that additional ethical safeguards were a legal and welcome mechanism for limiting euthanasia (Belgian Advisory Committee on Bioethics, 2014).

### 5.5.5 Euthanasia Guidelines Have Conflicted with the Law in the Netherlands

In 2012, the Royal Dutch Medical Association (KNMG) proposed adapting the euthanasia law to require that the second evaluating physician be able to communicate with the patient, which would be impossible in cases where the patient has lost capacity (Sheldon, 2013). The KNMG also advised its members not to perform euthanasia in cases where they could not communicate with the patient, recognizing that this opinion represented a “professional norm [that was] more stringent than the legal criteria” (Lewis & Black, 2013). This conflict between medical association guidelines and the law generated confusion for physicians, and prompted the government to launch a research project aimed at clarifying the issues surrounding AEDs. The research was a collaboration of numerous professional organizations, resulting in a consensus document (the *Written Request for Euthanasia Guide*) published for physicians by the government and the KNMG in December 2015 (KNMG *et al.*, 2015), with a version for citizens published in January 2016 (KNMG *et al.*, 2016; Onwuteaka-Philipsen *et al.*, 2017). The guide aligns with the current euthanasia law and also supports the interpretations made by the RTE (i.e., an AED can still be followed even if it is no longer possible to communicate with the patient, as long as the due care criteria are fulfilled). Given that the KNMG was involved in creating the guide, it can be inferred that the organization no longer adheres to the strict position it took in 2012 (Onwuteaka-Philipsen *et al.*, 2017).

### 5.5.6 Lessons from the Netherlands and Belgium: Updating AEDs Is Recommended, but a Cumbersome Renewal Process May Limit Use

In the Netherlands, the law does not require people to regularly update their AEDs, but the RTE *Code of Practice* and the *Written Request for Euthanasia Guide* recommend it (RTE, 2015c; KNMG *et al.*, 2016). Both documents caution that family members and physicians may doubt whether an AED still reflects a patient’s wishes if the directive is old. Thus, they advise patients to keep their written AED up to date, confirm its contents orally, and continue end-of-life conversations with physicians and family members (RTE, 2015c; KNMG *et al.*, 2016).

In contrast to the Netherlands, Belgian law requires the renewal of AEDs every five years (Gov. of Belgium, 2002). Since 2010, the CFCEE has expressed regret about being unable to find a more effective mechanism for drafting,

registering, and renewing AEDs, the complexities of which, they state, have limited their use in Belgium (CFCEE, 2010, 2016). Considering both the Dutch and Belgian experiences, it would seem that, while frequent renewal is beneficial and encouraged for AEDs, mandated requirements for drafting, registration, and renewal may become burdensome and detract from their effectiveness.

## **5.6 EUTHANASIA IN PATIENTS WITHOUT DECISION-MAKING CAPACITY: DUTCH CASE STUDIES**

Direct evidence on the practice of following AEDs for conscious patients who lack decision-making capacity is sparse. Only six publicly available case reports from the Netherlands describe patients who received euthanasia based on their written AED and were registered by the RTE as decisionally incompetent. This section analyzes these case reports (as well as several others that involved some uncertainty about the patient's capacity to confirm their euthanasia wish). The analysis examines elements present when a case proceeded smoothly and elements present (or absent) when issues arose. Although the number of cases is too small to carry out any statistical analyses, the qualitative evidence they provide is still important.

The RTE registers euthanasia cases that involve decisionally incompetent patients, but they do not include these numbers in their annual reports. The Working Group was able to obtain this information through a personal communication with the RTE. In 2009, the RTE annual reports started including the number of euthanasia cases involving dementia patients, but most of these patients still had decision-making capacity. It was not until 2011 that the first patient with severe dementia received euthanasia based on an AED (Menzel & Steinbock, 2013).

There are five Dutch RTEs, which review all reported euthanasia cases by examining the actions of the physician against the six due care criteria and determining whether they followed the criteria (RTE, n.d.-a, n.d.-b). As mentioned, detailed descriptions of selected cases are included in the RTE annual reports and on their website; the cases examined by the Working Group for this analysis involved patients whose desire for euthanasia was expressed in a written AED, and whose decision-making capacity was questionable at the time euthanasia was provided. See note below Table 5.3 for information on inclusion/exclusion criteria of cases analyzed.

Table 5.3

**Dutch Euthanasia Cases\* Involving Patients with Absent or Questionable Decisional Competence**

Case Number	Reference	Patient's Condition(s)	Patient's Decisional Capacity at Time of Assessment by Physician/Consultant(s)	Due Care Criteria Complied With?
2012-08	(RTE, 2012c)	Huntington's disease with dementia	Patient could no longer clearly express her euthanasia wish and it was unclear if she understood anything	No
2014-02	(RTE, 2014b)	Cognitive disorders, aphasia	Patient could no longer clearly express her euthanasia wish and decisional competence was questionable	No
2016-85	(RTE, 2017d)	Alzheimer's	Registered as decisionally incompetent by RTE	No
2017-103	(RTE, 2017a)	Alzheimer's, COPD, aphasia	Registered as decisionally incompetent by RTE	No
2011 – Case 7	(RTE, 2012a)	Alzheimer's	Patient could no longer clearly express her euthanasia wish and decisional competence was questionable	Yes
2012-09 (Case 4)**	(RTE, 2013)	Dementia	Patient could no longer clearly express her euthanasia wish and decisional competence was questionable	Yes
2014-35	(RTE, 2015d)	Alzheimer's	Patient could no longer clearly express her euthanasia wish and decisional competence was questionable	Yes
2015-37	(RTE, 2015a)	Frontotemporal dementia, aphasia	Patient could no longer clearly express her euthanasia wish and decisional competence was difficult to judge due to language disorder	Yes
2015-68	(RTE, 2015b)	Alzheimer's, post-herpetic neuralgia, language disorder	Patient could no longer clearly express her euthanasia wish and decisional competence was difficult to judge due to language disorder	Yes
2016-18	(RTE, 2016d)	Alzheimer's	Registered as decisionally incompetent by RTE	Yes
2016-38	(RTE, 2016a)	Alzheimer's	Registered as decisionally incompetent by RTE	Yes
2016-39	(RTE, 2016b)	Alzheimer's, aphasia	Patient could no longer clearly express her euthanasia wish and decisional competence was questionable	Yes
2016-62	(RTE, 2017d)	Alzheimer's	Registered as decisionally incompetent by RTE	Yes
2017-14	(RTE, 2017b)	Dementia	Registered as decisionally incompetent by RTE	Yes

*continued on next page*

Case Number	Reference	Patient's Condition(s)	Patient's Decisional Capacity at Time of Assessment by Physician/Consultant(s)	Due Care Criteria Complied With?
2017-128	(RTE, 2017c)	Vascular dementia, recurrent strokes, aphasia	Patient could no longer clearly express his euthanasia wish and decisional competence was questionable	Yes
2018-21	(RTE, 2018c)	Alzheimer's	Patient could no longer clearly express her euthanasia wish and decisional competence was questionable	Yes

\* Case Selection: All cases (66 in total as of May 3, 2018) listed under the *dementia* category on the RTE website were reviewed. The online database contains cases from 2012 to the present; one case from 2011, included only in the Dutch version of the RTE 2011 annual report (RTE, 2012a), was also reviewed. Two additional cases not classified under the dementia category (but still involving cognitive impairment) were identified by the Working Group (Cases 2012-08 and 2014-02). Thus, in total, 69 cases were reviewed, of which 16 involved patients with absent or questionable decisional competence. To be included in this analysis, a case had to fulfil the following criteria: (i) the patient had expressed their desire for euthanasia in a written AED, and (ii) the patient was registered as decisionally incompetent by the RTE (6 cases fulfilled this criterion) or the patient's capacity to clearly confirm their euthanasia wish was uncertain (either because physicians had differing opinions or because they had difficulty judging the patient's decisional capacity due to communication issues; 10 cases fulfilled this criterion). Cases were excluded for the following reasons: (i) the case concerned a patient who had decisional capacity with respect to their euthanasia request; (ii) the patient had not written an AED; (iii) the AED was mentioned briefly in the case report and did not appear to have played a role in deciding whether the patient should receive euthanasia; or (iv) the AED was declared invalid because there were doubts about the patient's capacity when it was written.

\*\* In earlier RTE annual reports, cases were assigned a new number based on the order in which they appeared in the report. In the English version of the annual report, Case 2012-09 appears as Case 4.

According to the RTE, physicians complied with the due care criteria in 12 of the 16 cases (Table 5.3). To create Table 5.4, the Working Group extracted characteristics from these 16 cases that were associated with compliance or lack thereof. Not all of the characteristics in each group were present in every case. At the time of this report's publication, the Public Prosecution Service was still investigating two of the cases in which physicians did not comply with the due care criteria — Case 2016-85 and Case 2017-103 (Openbaar Ministerie, 2018).

Table 5.4

**Dutch Euthanasia Cases Relying on AEDs: Compliance with Due Care Criteria**

Characteristic	Due Care Criteria Complied with (n=12)	Due Care Criteria Not Complied with (n=4)
Specificity of AED	<ul style="list-style-type: none"> <li>• Specific details describing circumstances that would warrant euthanasia</li> </ul>	<ul style="list-style-type: none"> <li>• No specific details (e.g., patient only states one condition for euthanasia, such as moving to a nursing home)</li> </ul>
Frequency of discussion about euthanasia	<ul style="list-style-type: none"> <li>• Frequent discussions with physician and family members</li> <li>• Physician takes time to guide patient</li> </ul>	<ul style="list-style-type: none"> <li>• Euthanasia not discussed enough when patient still decisionally competent</li> </ul>
Documentation of euthanasia discussion/ updating of AED	<ul style="list-style-type: none"> <li>• Discussions with physician well documented in patient's records</li> <li>• Written AED updated often</li> </ul>	<ul style="list-style-type: none"> <li>• Discussions with physician never or rarely recorded</li> <li>• Written AED not updated — in one case, was 20 years old</li> </ul>
Consistency of patient's wish for euthanasia	<ul style="list-style-type: none"> <li>• Patient does not waver in wish for euthanasia while decisionally competent and expresses wish to die until final moments (even if non-verbal)</li> </ul>	<ul style="list-style-type: none"> <li>• Patient does not express a clear, continuous wish for euthanasia throughout illness and wishes are unclear once capacity is lost</li> </ul>
Degree to which physician performing euthanasia is familiar with patient	<ul style="list-style-type: none"> <li>• Physician is familiar with patient's personality and situation</li> <li>• If GP unwilling to perform euthanasia, SLK physician contacted early enough to observe patient thoroughly</li> </ul>	<ul style="list-style-type: none"> <li>• Physician is unfamiliar with patient (e.g., ECP at nursing home)</li> <li>• SLK physician (if needed) contacted too late, when patient already decisionally incompetent</li> </ul>
Strength of consultation	<ul style="list-style-type: none"> <li>• Physician seeks extra expertise if needed (e.g., geriatrician, neurologist, psychogeriatric specialist), using as many as three consultants</li> <li>• Physician begins consultation process early so consultant can observe patient's suffering over time</li> </ul>	<ul style="list-style-type: none"> <li>• Physician does not take extra time, use extra consultants, or begin consultation process early enough to confirm that euthanasia is appropriate</li> </ul>
Clarity regarding unbearable suffering	<ul style="list-style-type: none"> <li>• Patient is clearly sad, frustrated, angry, distressed, and anxious about continued decline</li> </ul>	<ul style="list-style-type: none"> <li>• Patient did not clearly define what constitutes suffering in AED, so unclear if AED applies to patient's current circumstances</li> <li>• Patient's mood may be variable so suffering appears to be intermittent</li> </ul>
Behaviour of patient during procedure	<ul style="list-style-type: none"> <li>• Patient expresses acquiescence (may understand that euthanasia is occurring at that moment) and does not resist in any way</li> </ul>	<ul style="list-style-type: none"> <li>• Patient is unaware of what is happening and may appear distressed</li> <li>• Patient may resist</li> </ul>

Abbreviations: ECP (elderly care physician); GP (general practitioner); SLK (End-of-Life Clinic)

The analysis shown in Table 5.4 suggests some key factors, summarized below, that contribute to the RTE finding of compliance with the Dutch due care criteria.

### 5.6.1 Patient Identifies Specific Criteria in Their AED

In some of the cases where physicians complied with the due care criteria, patients prepared AEDs that listed a number of specific circumstances in which they would want euthanasia. For example, the Alzheimer's patient in Case 2016-62 listed the following circumstances:

[I]f he as a person were to change so much that he felt permanently unhappy, if he were to become aggressive and difficult, if he no longer recognised his loved ones, if he were to end up waiting for death, as had a close family member who also had Alzheimer's disease, if he were unable to take care of himself and became completely dependent on others, if he were suffering unbearably and without prospect of improvement.

(RTE, 2017d)

This level of detail revealed the type of existence that was unacceptable to the patient at the time that he wrote his AED. In contrast, the four cases with non-compliant physicians involved AEDs with broader conditions; the only specific criterion mentioned was placement in a nursing home. Because a nursing home placement alone is insufficient to assume unbearable suffering, using this as the sole condition for euthanasia was deemed problematic (e.g., RTE, 2014b).

### 5.6.2 Patient's Euthanasia Wish Is Often Discussed, Well Documented, and Consistent

In most cases that involved a judgment of compliance, patients discussed euthanasia often, sometimes from the moment they were diagnosed (e.g., RTE, 2015d), and these discussions were documented in their medical records. Their written AEDs were updated frequently and they consistently expressed their wish for euthanasia throughout their illness. Most of the case reports involving compliance indicate that patients communicated their wish for euthanasia until their final moments, either by stating this verbally or by conveying it behaviourally if they had lost the ability to speak.

In the four cases involving non-compliance, discussions about euthanasia sometimes occurred but were not recorded, AEDs were not updated, and patients did not make clear and consistent statements about euthanasia. In Case 2012-08, the patient had signed an AED in 2005 indicating the circumstances under which

she would want euthanasia, but it was not discussed regularly after this time, and in 2009, the patient stated that she “did not want a needle”<sup>10</sup> (RTE, 2012c). In addition, she never asked for euthanasia before it was performed in 2012, and at the time of the procedure, was unable to communicate her wishes in any way (RTE, 2012c).

### 5.6.3 Physician Is Familiar with Patient’s Situation and Takes Great Care in Consultations

Physicians whose actions were deemed compliant were more likely to be familiar with the patient and their circumstances. In Case 2014-35, the physician had known the patient for years and knew how much she valued her independence; thus, the physician was satisfied the patient considered her current situation unbearable. Even so, when one of the independent consultants expressed some doubt, the physician followed the consultant’s advice to have a third assessment done by a psychogeriatric specialist (RTE, 2015d).

Sometimes, however, a long-time physician may be unwilling to perform euthanasia or their patient may be under new care in a nursing home. In addition, some patients receive euthanasia through an End-of-Life Clinic (SLK). SLK clinics are mobile clinics that “offer euthanasia or assisted suicide to people whose request for assisted dying was first denied by their own physician” (Levenseindekliniek, n.d.). The Working Group notes that, when patients use these clinics, they usually do not have a long-standing relationship with the physician who provides them with euthanasia. While SLK clinics were involved in fewer than 5% of euthanasia and assisted suicide cases from 2012 to 2016, during this same time period, they were involved in 19% of cases in which the RTE found that due care criteria were not met (Miller & Kim, 2017).

Some precautionary measures may be taken to mitigate the risks of a new, unfamiliar primary physician. For example, in Case 2016-39, the SLK physician who was involved spoke to the patient four separate times to confirm the presence of unbearable suffering and a consistent, voluntary, well-considered euthanasia request (RTE, 2016b). In contrast, in Case 2014-02, the RTE ruled that the SLK physician involved “expended insufficient time and effort in this situation to confirm the unbearable nature of the patient’s suffering” (RTE, 2014b).

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10 Unofficial translation provided by Working Group member Trudo Lemmens.

#### **5.6.4 Suffering Is Evident and Patient Does Not Resist During Euthanasia Procedure**

In the four cases in which physicians did not comply with the due care criteria, the unbearableness of the patient's suffering was called into question. In Case 2014-02, the patient's mood was variable and communication with her was difficult due to cognitive disorders and aphasia caused by a stroke (RTE, 2014b). In Case 2017-103, after observing video footage of the patient and meeting with her, the consulting physician disagreed with the SLK physician about the patient's degree of suffering (RTE, 2017a). All four cases were clouded by an imprecise indication in the AED of what constituted unbearable suffering for the patient, infrequent discussion about euthanasia, and inconsistent or unclear wishes throughout, making it difficult for the consulting physician to judge whether the patient was suffering. In cases where physicians complied, it was deemed that the patients were clearly suffering unbearably and wished for euthanasia even as the procedure was performed. The physician in Case 2016-85 was non-compliant, in part because she did not stop the procedure when the patient responded negatively (RTE, 2017d).

#### **5.6.5 A Judgment of Non-Compliance is More Likely in Cases Involving AEDs**

One of the Working Group's observations drawn from this case analysis was the frequency with which due care was not followed in all euthanasia cases compared to those that relied on AEDs. From 2002 to 2017, due care criteria were not complied with in 0.2% (n=101) of all euthanasia and assisted suicide cases (55,872 in total). Of the analyzed cases that involved AEDs and patients with questionable decisional competence, 25% (4 of 16) were non-compliant with due care criteria. However, not all cases involving doubt or uncertainty result in a judgment of due care not met; moreover, the Working Group's analysis was not exhaustive and likely missed some cases in which AEDs played a role. Nonetheless, this comparison still suggests that issues are more likely to arise when a person cannot provide express consent immediately prior to receiving MAID.

## 5.7 CHAPTER SUMMARY

Canadian evidence on ACP and advance directives is wide-ranging and varies in strength. It nonetheless helps inform the contours of ARs for MAID, bringing forward constraints within Canada's legal and regulatory landscape and challenges presented by Canada's existing mechanisms for advance consent, which are provincially/territorially regulated through legislation for advance directives.

Because ARs for MAID are not legally valid in Canada, direct evidence on implementation comes from other countries. Thus, the Working Group has examined the pathways taken by these permissive countries, highlighting how such pathways have been contingent on the countries' specific legal and regulatory frameworks. Data from the Netherlands show that there have been very few cases of conscious patients receiving euthanasia based on AEDs, and, among these few cases, there has been controversy. In the Netherlands, the practice of following AEDs for conscious but incapacitated patients is contentious, and guidelines for appropriate practice are still being debated.

# 6

## **Allowing or Prohibiting Advance Requests for MAID: Considerations**

- **Potential Impacts of Allowing or Prohibiting Advance Requests for MAID**
- **Potential Safeguards for Advance Requests for MAID**
- **Chapter Summary**

## 6 Allowing or Prohibiting Advance Requests for MAID: Considerations

### Key Findings

ARs for MAID may give rise to a range of positive and negative impacts, which could be experienced not only by those requesting MAID, but also by those responsible for deciding if and when to follow through with the request, and by society as a whole. Little evidence exists as to the likelihood of potential impacts; they are plausible but conjectural.

Safeguards, realized through legislation, clinical processes, or support programs, might help address some of these negative impacts; however, there is little evidence of their efficacy.

There is a distinction between (i) safeguards meant to ensure that those who genuinely wish to receive MAID through an AR could have access to a fair, safe, comprehensive process that they and their families could trust; and (ii) safeguards meant to ensure that ARs for MAID could function as intended within the healthcare system.

Impacts and safeguards would vary depending on the timing of the AR for MAID. As the period between creating and implementing a request lengthens, the risk increases that someone might receive MAID when no longer desired. Broader eligibility criteria for ARs for MAID would require more safeguards.

The Working Group was asked to consider potential impacts of permitting or prohibiting ARs for MAID in Canada, as well as potential risks and safeguards. These considerations require broad examination of the evidence; however, as noted in preceding chapters, there is little direct experience worldwide when it comes to implementing advance requests for assisted death. Of the four countries that allow AEDs, two (Belgium and Luxembourg) limit their application to cases of irreversible unconsciousness, and one (Colombia) allows them only in the context of imminent death. Furthermore, there are only six documented cases of conscious people who lacked decision-making capacity receiving euthanasia based on an AED, all of which occurred in the Netherlands, and some of which were subject to controversy. The limited uptake of the practice and the controversy surrounding such cases suggest that implementing ARs for MAID in Canada might be challenging.

Given the limited information on practical experience, the Working Group bases its evaluation of potential impacts and safeguards on a wide body of knowledge, drawing on members' professional expertise and experience to give weight to different sources of evidence. Where possible, empirical studies are used to examine impacts; however, also considered are ethical and legal arguments, anecdotal accounts, claims, and opinions, some of which emerged from the CCA's Call for Input. Finally, in summarizing what is known, unknown, and may never be known about these impacts and safeguards, the Working Group takes into account the current Canadian legal and clinical framework for advance directives, using this information to inform discussions where appropriate.

### **6.1 POTENTIAL IMPACTS OF ALLOWING OR PROHIBITING ADVANCE REQUESTS FOR MAID**

Whether ARs for MAID are prohibited or permitted, there will be potential impacts of varying significance on patients, caregivers, and healthcare practitioners; on specific groups of people; on healthcare systems; and on society as a whole. These potential impacts might be related to the views of people and society on autonomy in end-of-life decision-making, suffering, the burden on others responsible for following through with an AR for MAID, the potential for fostering stigma, and the motivation for making a request.

Over the short term, impacts associated with allowing ARs for MAID are unlikely to be fully recognized, given the need for long-term recording and analysis of data. Some impacts may never be fully known or understood. There is, however, already some evidence of impacts associated with Canada's prohibition of ARs for MAID. In the clinical experience of some Working Group members, and as expressed in responses to the Call for Input, ARs for MAID are in demand (e.g., Dying with Dignity Canada, 2017a; Right to Die Society of Canada, 2017), and predicted increases in the prevalence of neurodegenerative conditions will likely increase that demand in the future (Section 3.2.1). Eligible patients who have been approved for MAID have identified the time gap between approval and the procedure (including the mandated 10-day waiting period) as a source of anxiety and suffering (UHN, 2017). Healthcare practitioners concerned with ensuring and documenting decision-making capacity have also found this time gap burdensome (CAMAP, 2017). A more in-depth assessment of the impacts of prohibiting ARs for MAID, however, requires a closer look at the experiences of those caring for patients with capacity-limiting conditions, which is beyond the scope of this report. Thus, most of this section focuses on the potential impacts of permitting ARs for MAID.

### 6.1.1 ARs for MAID Could Support Autonomy in End-of-Life Decision-Making

In the preamble to Bill C-14, Parliament recognizes “the autonomy of persons who have a grievous and irremediable medical condition that causes them enduring and intolerable suffering” as a reason for allowing MAID in Canada (GC, 2016). Allowing ARs for MAID would give people who anticipate loss of decision-making capacity the opportunity to exercise that autonomy. Indeed, some feel that prohibiting ARs for MAID denies people the end-of-life autonomy that MAID is, in their view, meant to secure (e.g., Dying with Dignity Canada, 2017a). However, questions of autonomy (and relational autonomy) become more complex when applied to those who have lost decision-making capacity, and would have special implications for ARs for MAID.

#### Individual and Relational Autonomy

As discussed in Section 3.4.1, there is diversity in how society views the concept of autonomy. In the individualistic view, autonomy concerns the right of a person to make a decision based on their values and beliefs, without interference from others (Beauchamp & Childress, 2013). People may feel that they have the right to a peaceful, dignified death, as long as they have expressed their wish in an AR for MAID. Some feel that it is unfair to deny them the right to exercise their autonomy just because they have lost the capacity to make medical decisions (e.g., Right to Die Society of Canada, 2017). Many of the personal stories shared by Dying with Dignity Canada in its submission to the Call for Input expressed this sentiment — the unfairness of losing the option to receive MAID (Dying with Dignity Canada, 2017a).

Sherwin (1998) expresses another viewpoint, arguing that relationships are so integral to the human condition that true individualism is not possible. Relational autonomy considers the decisions of an individual to be a product of their interpersonal relationships and the socio-political context in which those decisions are made (Sherwin, 1998; Rodney *et al.*, 2013). Deschamps (2016) points out that MAID is an inherently relational act, involving at least the relationship between a physician and patient. A relational approach to autonomy supports the idea that autonomy “should always be seen within the network of a person’s relations and world” (Gastmans & De Lepeleire, 2010).

With respect to ARs for MAID, the relational view of autonomy is particularly relevant because the process would involve not only the patient and healthcare practitioner but also a third party who is responsible for interpreting and advocating for the previously expressed wishes of the person who has lost decision-making capacity. ARs for MAID, therefore, cannot guarantee that the wishes

of a patient who has lost capacity will be respected without the involvement of others, who must interpret instructions that, as noted in Sections 5.5 and 5.6, can often be unclear (Gastmans & De Lepeleire, 2010).

### Precedent Autonomy Versus Current Autonomy

Another autonomy-related consideration relevant to ARs for MAID is the concept of precedent autonomy (Section 3.4.1). People can change their preferences or wishes over time to such a degree that their AR for MAID no longer appears to apply to them. This is especially pertinent to people with dementia, who may express radically different views as the disease progresses. Dworkin (1993) argues that the interests a person expressed while capable take precedence over the interests of their future incapable self (precedent autonomy). ARs for MAID would thus protect the autonomy of the person who now lacks capacity by providing a means of respecting their previous, competent wishes. However, some disagree with dismissing the autonomy of the incapable person in favour of their prior, expressed wishes, arguing that people who lack decision-making capacity can still hold personal values and interests that should be respected (e.g., Dresser, 1995; Jaworska, 1999). This perspective suggests that following an AR for MAID might actually strip decisionally incapacitated people of their autonomy. Menzel and Steinbock (2013) note that contention largely arises when the written wishes of the person conflict with their behaviour after loss of decision-making capacity.

#### 6.1.2 ARs for MAID Could Provide Additional Relief from Suffering and Distress

A potential positive impact of allowing ARs for MAID is relief from suffering for those who wish to receive an assisted death. However, because it is impossible to gauge the relief of suffering in patients who have died, even the jurisdictions that allow AEDs cannot offer any evidence of this impact. The available evidence comes only from patients who are experiencing suffering (or caregivers who are observing it) where MAID is available but ARs for MAID are not. In addition to information collected through a hospital-based MAID program (Li *et al.*, 2017), the Working Group relied on personal, anecdotal experiences as evidence.

The Working Group notes that, while some patients believe an AR for MAID would relieve suffering and enable them to die with dignity, others may feel they would achieve a dignified death without access to MAID. Thus, the key element for ensuring that all patients die with dignity is not to provide MAID for everyone, but to give people the opportunity to choose MAID if that is what they desire.

### ARs Could Relieve Suffering for a Wider Patient Population

A potential positive impact of allowing ARs for MAID, according to some, is the relief of suffering for patients who are currently ineligible for MAID due to capacity loss. Permitting ARs would give this patient population the same access to MAID as patients with decision-making capacity. In their testimonies to Parliament's Special Joint Committee on Physician-Assisted Dying, some witnesses expressed concern that regulation intended to protect vulnerable people could also prevent those same people from accessing MAID, even under circumstances where they would otherwise be eligible (SJCPAD, 2016).

### ARs Could Relieve Distress Caused by Fear of Losing Capacity Before MAID Is Provided

Based on their experience with MAID cases, Toronto's University Health Network identified several reasons why patients continued to experience physical and psychological suffering even after MAID approval (UHN, 2017). In some cases, those who were eligible did not receive MAID because they lost decision-making capacity; frustrated by the requirement to be legally competent but wanting to live while they still had capacity, they opted to wait for an obvious sign of their impending deterioration before choosing a date. Other patients waited for several months after approval before asking to receive MAID, and faced a time-consuming, anxiety-provoking re-evaluation of eligibility. In most cases, patients refused pain medication to ensure that they retained the capacity to provide informed consent (UHN, 2017). Patients struggling with the logistics of their MAID request may experience anxiety and distress. However, for some patients, even those uncertain about whether or when to schedule the procedure, MAID approval was able to relieve distress associated with losing control (Li *et al.*, 2017).

For those who are actively considering MAID, the fear of losing capacity may be strong enough to compel some patients to request the procedure earlier than they would have preferred (Li *et al.*, 2017). In its submission to the Call for Input, Dying with Dignity Canada (2017a) suggested that others have dealt with this fear by taking their own lives while they were still able to.

### ARs for MAID Could Relieve Suffering by Giving Patients a Feeling of Control

Some patients in the earlier stages of a disease, or even healthy people, may not be ready to request MAID for years or decades, but are nonetheless suffering. Dying with Dignity Canada (2017a) shared many personal stories from patients and caregivers who spoke of the knowledge (or fear) that they would have a long, painful, undignified illness, and of their frustration at not being able to

write an AR for MAID that would be respected. Some provided descriptions of a loved one's slow decline and described their desire to avoid the same fate (e.g., Dying with Dignity Canada, 2015). A type of suffering consistently mentioned in these stories was loss of dignity (e.g., Dying with Dignity Canada, 2016, 2017b). Li *et al.* (2017) report loss of dignity, inability to enjoy life, and a wish to avoid burdening others as common reasons for MAID requests; few patients asked for MAID to relieve pain or other symptoms that could not be controlled adequately. The most common reason for a request was loss of autonomy, which was cited by 80% of the patients who underwent an eligibility assessment and 95% who received MAID (Li *et al.*, 2017).

Some patients describe the relief they feel knowing that MAID is a possibility. Although these stories do not speak to ARs for MAID, but rather to MAID in general, they still illustrate the comfort that can be provided by the option of an assisted death at some point in the future. One such patient is Will Pegg, a British Columbia resident with metastatic bone cancer, who received MAID in late September 2018. He spoke of his relief in knowing he could end his life when he wished:

Stefanie [Pegg's physician] gave me my life back. And I think the perception might be that MAID is about dying. But as far as my personal experience of it, it is about living rather than me spending my energies worrying about clear torment to come. In my situation, it's allowed this year to flower. Stefanie is in the position to accord me mercy, which is an incredible gift in the midst of dark circumstances.

(CBC Radio, 2017)

In discussing their interactions with two patients who requested MAID at the Princess Margaret Cancer Centre in Toronto, Li and Kain (2018) note the great relief these patients felt after learning they were eligible. One was better able to tolerate his symptoms and "had more patience and respect for the limitations of his body;" the other had been refusing visits with friends and family because of her anxiety and distress about dying, but, after approval, felt so well that she was able to enjoy time with her grandchildren (Li & Kain, 2018).

These stories suggest another potential positive impact of allowing ARs for MAID: the possibility that some patients' mental states, and by extension quality of life, might improve when they feel they have some control over their end of life. For those who value the level of control that an AR for MAID would provide, allowing this practice might reduce their fear of losing capacity and suffering before their death and permit them to find more enjoyment in their remaining time.

### 6.1.3 ARs for MAID Could Place a Burden on Those Making Life-Ending Decisions for Others

Care teams comprising loved ones, the SDM, and healthcare practitioners would shoulder the responsibility of implementing a patient's AR for MAID. They would need to decide if and when MAID was an appropriate course of action based on their knowledge of the patient's wishes and their evaluation of the patient's current state. Furthermore, healthcare practitioners would be required to deliberately end the life of a patient who could not consent to this action by administering a substance unrelated to treatment. Thus, one potential impact of permitting ARs for MAID is the burden it could place on people who must make the irreversible decision to actively end someone else's life.

#### Family Members and SDMs

Several submissions to the Call for Input expressed concern about the burden that ARs for MAID could place on family members and SDMs. The Canadian Society of Palliative Care Physicians (CSPCP) emphasized that SDMs are not only given a great responsibility, they are also expected to perform their role under challenging circumstances. The ability to make the difficult choices that ARs for MAID entail may be compromised if SDMs are depleted financially, emotionally, or physically (i.e., experiencing caregiver burnout) (CSPCP, 2017). This issue is compounded by the lack of processes in Canada that ensure SDMs are adequately supported in dealing with their loved one's advance directive (CSPCP, 2017).

Knowledge of the burden that AEDs place on family members and SDMs is scarce. Some research from the Netherlands shows that a majority of relatives of dementia patients ask that physicians not provide euthanasia when the patient has an AED, instead viewing the AED as justification to forego life-sustaining treatment (Rurup *et al.*, 2005; de Boer *et al.*, 2011) (Section 5.5.1). Relatives may feel less implicated in the death when no overt action is taken to end the life of the patient. As one relative interviewed in de Boer *et al.* (2011) states: "As long as he still had these moments he enjoyed, I actually saw it as murder. I couldn't find it in my heart to ask for euthanasia."

Though research on caregiver burden in the context of AEDs is lacking, there have been studies on the effects of making medical treatment decisions for others. Even for situations without life or death consequences (e.g., deciding whether to move a relative with dementia into a care facility), substitute decision-making can be challenging and distressing, and end-of-life decisions may be even more difficult (Lord *et al.*, 2015). SDMs may experience stress and feelings of guilt and doubt (Wendler & Rid, 2011). Negative emotional burdens are

reduced when the SDM and care team have a collaborative relationship, when the SDM is familiar with the patient's treatment preferences, and when those preferences align with the SDM and care team's estimation of what is in the patient's best interest (Wendler & Rid, 2011; Lord *et al.*, 2015).

### Healthcare Practitioners

Organizations that responded to the Call for Input also expressed concern about the burden on physicians should ARs for MAID be allowed in Canada. The CPSO flagged a practical issue (discussed in Section 4.3.7), concerning the conduct of a patient during the MAID procedure:

In practice, there can be a striking contrast between a patient's prior capable wish and the patient's conduct when incapable. Specifically, there may be situations where a patient has expressed a prior capable wish to receive a particular treatment, but then physically recoil[s] or verbally protest[s] when clinicians attempt to provide that very treatment. Clinicians will need clarity about how to proceed in these instances in relation to MAID.

(CPSO, 2017b)

The Canadian Medical Protective Association (CMPA) raised a concern about liability for healthcare practitioners willing to provide MAID based on an AR. It cautioned that if ARs for MAID were to be permitted, it would be necessary to clearly define the process for following them and the circumstances in which it would be reasonable to rely on them (CMPA, 2017b).

The CSPCP raised the problem of putting more pressure on MAID assessors and providers, particularly by allowing increasingly complex requests that would require capacity assessments (CSPCP, 2017). Based on the CSPCP's personal communication with current MAID providers, many are already overburdened (CSPCP, 2017); however, a member survey conducted by the Canadian Association of MAID Assessors and Providers (CAMAP) (2017) suggested that most would be willing to take on the challenge of ARs for MAID. CAMAP surveyed 135 MAID assessors and providers from its larger membership list, and received 79 responses from those who described themselves as currently active (either as an assessor, provider, or both). Of those, 82% stated that they would be willing to assess patients who had made an AR for MAID but had lost the capacity to make their own healthcare decisions. Furthermore, 76% would be willing to provide MAID to an eligible patient who lacked capacity but had an AR for MAID (CAMAP, 2017).

Few physicians worldwide have implemented AEDs, particularly in situations involving conscious but decisionally incapacitated patients, and because no healthcare practitioner in Canada has implemented an AR for MAID, there are not enough data to assess the burden of this task on physicians. The available evidence on the emotional experiences of physicians who have performed euthanasia is limited to patients with capacity (see Section 5.5.2). In these studies, physicians described some negative emotions associated with performing euthanasia (e.g., dread, anxiety, loneliness), but they also mentioned some positive ones (e.g., satisfaction, relief associated with feeling that they had been able to help the patient). Section 5.5.2 also discusses the reluctance of Dutch physicians to comply with AEDs for patients with advanced dementia. Physicians cited difficulty in judging the suffering of another and in determining the correct moment to implement an AED as reasons for this lack of compliance (de Boer *et al.*, 2010a); these two reasons were also identified in the Call for Input and are discussed in the next sub-section.

### Nature of Emotional Burden

In this sub-section, the Working Group considers the nature of the potential emotional burden placed on third-party decision makers. Would permitting ARs for MAID make SDMs and healthcare practitioners responsible for decisions that are too difficult to make for another person? The Call for Input identified two key decisions that would be particularly challenging — deciding when someone has met the conditions described in their AR for MAID and whether someone is suffering intolerably.

The Toronto Catholic Doctors Guild (2017) expressed concern about the level of interpretation that ARs for MAID would require. They argued that patients, and even experienced clinicians, could not predict all the different medical circumstances they might encounter, nor how they might respond to each situation (TCDG, 2017). The College of Registered Nurses of Manitoba (CRNM) raised the same concern, stating that “it would be difficult to codify the entire set of possible circumstances under which a clinician could act with ethical certainty on an advance request for MAID” (CRNM, 2017). However, the CRNM still felt that “it should be possible to set some criteria to increase the clinician’s confidence that provision of MAID is consistent with the patient’s values and wishes” (CRNM, 2017). Ultimately, according to the CRNM, clinicians have to ask themselves how comfortable they are with some level of uncertainty.

Canada's current legal framework for MAiD relies on a subjective judgment of suffering by patients themselves. How might this translate to a situation in which patients no longer have the capacity to evaluate their situation? In its submission to the Call for Input, the Canadian Association for Community Living (CACL) felt that it would be too difficult to establish whether advanced dementia patients were suffering intolerably, and was opposed to allowing someone to make this judgment on behalf of another person (CACL, 2017). The CSPCP (2017) emphasized that "we have no objective means of confirming whether an incapable person's suffering is 'intolerable' to the point that he or she would want MAiD." The need to interpret suffering in another person (which is very difficult due to its subjective, personal nature) could be substantially reduced if a patient clearly defined the conditions that represented intolerable suffering to them in their AR for MAiD. While a patient's care team would still need to interpret these conditions and decide whether the patient had met them, less interpretation of the patient's suffering would be required if their request was clear on this matter.

#### 6.1.4 ARs for MAiD Could Change How Society Views People with Capacity Loss

Stigma is "the situation of the individual who is disqualified from full social acceptance" (Goffman, 1963). Stigma is driven by stereotypes, prejudice, and discrimination (Benbow & Jolley, 2012). People with Alzheimer's disease or dementia, it is believed, are more susceptible to being taken advantage of, physically or verbally abused, ignored or dismissed, and socially rejected or avoided compared with those with physical health conditions (Alzheimer Society of Canada, 2017). According to Post (1995), people with dementia are excluded from society due to "a culture that is hypercognitive in its values and emphasizes productivity," making it "easy to think that people with dementia lack any moral significance."

A dementia diagnosis may lead people to write an AR for MAiD "because of fears of not getting adequate care or becoming burdens on others" (CACL, 2017). McPherson *et al.* (2007) note, in a systematic review focusing on end of life, that being a "self-perceived burden" corresponds to feeling a loss of dignity, suffering, and a "bad death." Becoming a burden on family, friends, or caregivers is stated as a reason for seeking physician-assisted death in Oregon 42.2% of the time (of 991 deaths from 1998 to 2016) (Gov. of OR, 2018a). Physical disability is a risk factor for suicidal ideation (Russell *et al.*, 2009), and people with disabilities are more vulnerable to feeling that they are a burden to others (Khazem *et al.*, 2015).

At the same time, providing significant care can be a burden to caregivers. It is financially, emotionally, and physically challenging to provide round-the-clock care and it is reasonable to want to avoid burdening loved ones with years of caring for someone with severe dementia (Menzel, 2018). Indeed, many of the letters and stories submitted by Dying with Dignity Canada (2017a) to the Call for Input cite the benefit that people feel they could provide to their loved ones by ending their life early (e.g., Dying with Dignity Canada, 2015). There is concern, however, that ARs for MAID, rather than serving those reasonable interests, could become a release valve for the societal failure to provide adequate support or care for those with neurocognitive declines and their families.

The evidence collected also suggests a further concern that permitting ARs for MAID could devalue the lives of people with dementia or other neurocognitive deficits. That is, by giving someone access to MAID because they anticipate a decline in mental capacity, society tacitly approves of the notion that life with a decline in mental capacity is not worth living, contributing to the stigma associated with such a decline. CACL raised this concern in its Call for Input submission, stating that “[l]egalization of AEDs would set stigmatizing social norms that those with dementia are burdens and terminating their lives is justified” (CACL, 2017). Similarly, Schutten (2016) argues that “assisted suicide, particularly for those with disabilities or diseases, is [...] inherently value-laden. Legalizing assisted suicide for such people is a value judgement about their societal worth and is discrimination in a lethal way.”

It is difficult to determine whether permitting ARs for MAID would result in devaluation of the lives of people with neurocognitive declines. However, *Toujours Vivant-Not Dead Yet* (2017) expressed concern that advance directives, as currently used in Canada, already endanger ill and disabled people, whose lived experiences of biases in the healthcare system have resulted in lower-quality treatment or the application of DNR orders without consent. The CSPCP (2017) has also raised the concern that “the current advance care planning situation has large limitations that will not support safe decision making in MAID.” In its review of vulnerability, CACL (2016) recognized a rapid increase in cases of dementia, high rates of depression among seniors, and elder abuse as three factors contributing to a predicted increase in the incidence of financial and other forms of abuse against people with disabilities

### 6.1.5 ARs for MAID Could Be Written or Followed for the Wrong Reasons

As suggested above, social environment may affect someone's underlying motivation to create an AR for MAID. According to Gastmans and De Lepeleire (2010), Dutch experience indicates that “the risk of being discriminated against by society can motivate elderly people to draft an advance euthanasia directive.” Gastmans and De Lepeleire (2010) go on to wonder whether permitting ARs for MAID would put social pressure on people to write one as a moral duty, to avoid becoming a burden to their family or to the healthcare system. Additionally, reflecting on the Belgian experience, Vanden Berghe *et al.* (2017) speculate that the availability of euthanasia in and of itself may augment one's perception of intolerability, though this speculation was not in reference to AEDs (as they are only valid under circumstances of irreversible unconsciousness in Belgium).

Some people might create an AR for MAID if they feel it is the only way to avoid suffering due to a lack of appropriate care services. In its Call for Input submission, the CSPCP noted that “lack of consistent access to high quality palliative care (CHPCA, 2014a), including [...] dementia support for patients and caregivers (CNA, 2016) is well documented. Without these alternatives, a choice for MAiD by advance request [...] is not a true choice” (CSPCP, 2017). Similar sentiments were expressed at the Elders Circle hosted by the CCA on February 20, 2018. Elders noted the need for safe spaces where communities and caregivers can support their loved ones at end of life, and the lack of basic healthcare, palliative care, and mental health services in many communities. Elders also expressed concern that MAID could be seen as the only choice to alleviate suffering due to this lack of access to care.

The suggestion that a lack of support services drives some MAID requests in the Canadian healthcare system may not be hypothetical. In 2016, Archie Rolland, a man with advanced ALS, requested and received MAID (Laucius, 2016) because, as he stated, “the people here [a long-term care facility in Lachine, QC] don't understand ALS and can't look after me. It is unbearable” (Fidelman, 2016). An Ontario resident, Roger Foley, has filed a lawsuit accusing Victoria Hospital and the South West Local Health Integration Network of failing to provide “a care option that would relieve his intolerable suffering and promote his wellness, independence, and dignity in the community, with funding already available to him” (ONSC, 2018).

Mr. Foley alleges that the defendants have also offered to refer him for assisted suicide, rather than provide him the right to self-direct his home care (ONSC, 2018). While these cases highlight problems experienced by individuals, no conclusions can be drawn from them about support services in Canada as a whole. However, Section 2.3 highlights some concerns about unequal access to healthcare and end-of-life care.

There are also the motivations of an SDM to consider, particularly if an AR for MAID is valid outside of clearly defined circumstances, such as the prognosis of irreversible unconsciousness. An SDM would have to interpret whether the circumstances defined as intolerable suffering in the AR for MAID are fulfilled; the emotions, perceptions, and values of the interpreter might influence their decision. A joint submission to the Call for Input from the Christian Medical and Dental Society of Canada, the Canadian Federation of Catholic Physicians' Societies, and Canadian Physicians for Life (CMDS *et al.*, 2017) cited several studies that found that people with dementia tend to rate their own quality of life higher than their SDM does (Buckley *et al.*, 2012; Hongisto *et al.*, 2015; Bravo *et al.*, 2017b).

The burden on healthcare practitioners and family members caring for people with capacity loss may colour how they interpret the patient's experience. As former RTE member psychologist Berna van Baarsen states, "[i]t is a normal human fact that caregivers run up against their own limitations and cannot cope with it anymore"<sup>11</sup> (Nyst, 2018); this may influence an SDM's interpretation of an AR for MAID. Some are also concerned that an SDM may be motivated to use an AR for MAID to address problems such as a patient's difficult behaviour, a lack of availability of specialized care, or financial constraints on support services, whether for overtly sinister motives or due to exhaustion of resources affecting their interpretation of the AR for MAID.

### **6.1.6 ARs for MAID Could Create Confusion About the Role of the SDM**

In their submission to the Call for Input, the CPSO (2017b) considered the situation in which an SDM could request MAID, based on their knowledge of the patient's preferences, without a documented AR for MAID. This is not, however, how the Working Group defines an AR for MAID, which is a documented request for MAID created by a person prior to a loss of capacity. That said, current advance directives legislation varies across Canada with respect to the powers and limitations of SDMs (Table 5.1). Should ARs for MAID be allowed, the role of an SDM in implementation would differ among provinces and territories were it to be regulated through provincial and territorial legislation.

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11 Unofficial translation provided by Working Group member Trudo Lemmens.

In the clinical experience of some Working Group members, it is not always the patient who asks about MAID; the patient may be, through sedation and pain medication, completely unaware of what is going on. Some requests come from family or friends who are disturbed by the symptoms and process of dying, who perceive suffering, and who ask the physician to help their loved one die. This is an understandable request, but without knowledge of the patient's wishes, providing MAID in those circumstances does not respect autonomy. A request for MAID put forward by an SDM complicates questions of voluntariness and motivations, particularly in relation to people who lack decision-making capacity in the eyes of the law, such as those with severe intellectual disabilities, minors, and wards of the state.

A healthcare practitioner may also present MAID as an option without knowing the limits of the law. For example, in 2017, a Newfoundland woman, whose cognitively impaired daughter was very sick, claimed a physician raised MAID as a possibility for her daughter (who eventually recovered from her illness) (Bartlett, 2017). To be clear, MAID would not be legal in this situation, unless the daughter had the capacity to provide informed consent to MAID, had herself made a MAID request voluntarily, and met all other eligibility criteria. Were ARs for MAID to be allowed, lack of knowledge about MAID legislation among healthcare practitioners and patients' loved ones could negatively affect those who cannot speak on their own behalf. Conversely, failure to inform a person that MAID is an option under appropriate circumstances also limits a person's ability to make meaningful decisions about their end of life. Well-defined, legislated limits, along with education, in either the permission or prohibition of ARs for MAID, could provide healthcare practitioners and family members with clarity on end-of-life options.

## **6.2 POTENTIAL SAFEGUARDS FOR ADVANCE REQUESTS FOR MAID**

Having described potential positive and negative impacts of allowing ARs for MAID, the Working Group acknowledges that this is the point at which perspectives diverge. An assessment of the possible risks and benefits of ARs for MAID might make some people uncomfortable with allowing them under any circumstances. They might feel that the requirement for consent immediately prior to receiving MAID is necessary to avoid errors and abuse, and to meet the broad goals of Canada's legislation, such as recognizing the inherent value of every person's life. Others might believe that uncertainty in interpreting the MAID preferences of people with advanced dementia could create an

insurmountable ethical dilemma that makes ending someone's life in such circumstances particularly problematic. They might feel that, in this case, it would be preferable to err on the side of not providing MAID, since other actions could be undertaken to alleviate the person's suffering. In contrast, others might focus on the potential benefits of ARs for MAID, such as the alleviation of anxiety and intolerable suffering, and believe that various safeguards could be implemented to mitigate risks. Those favourable towards ARs for MAID, however, might not agree on the specific scenarios in which they should be permitted. As discussed in Chapter 4, some scenarios contain more uncertainty than others, and might therefore require more rigorous safeguards. Thus, those who are comfortable with ARs for MAID would need to consider the specific situations in which they should be permitted and the safeguards that would be required for each one.

This section identifies a range of potential safeguards, including those that are case-specific (whose main purpose would be to achieve the right outcome in a given case) and those at the system level (whose goal would be to ensure that ARs for MAID were operating within a well-functioning healthcare system and achieving their intended purpose in society). Some safeguards might be appropriate for legislation, while others might be best incorporated into a code of practice or other similar guidance document. While these proposed safeguards have the potential to reduce some of the uncertainties associated with ARs for MAID (Chapter 4), and address some of the potential negative impacts discussed in Section 6.1, their effectiveness has not yet been evaluated. Furthermore, some safeguards used in other countries may not transfer effectively to the Canadian context. Nonetheless, there is a foundation of principles, guidelines, and expert experience on which to establish the parameters of a safeguard regime were ARs for MAID permitted in Canada.

### **6.2.1 Measures to Reduce Uncertainty Through Well-Defined Access Criteria**

If ARs for MAID were to be permitted, one approach to reducing uncertainty would be to allow them only under a well-defined set of circumstances. Belgium and Luxembourg use this approach by only allowing AEDs to be implemented if patients are irreversibly unconscious. This access criterion mitigates many of the uncertainties surrounding ARs for MAID for two main reasons: (i) it removes the issue of precedent versus current autonomy, since an unconscious person does not have any awareness, nor any ability to express interests or enjoy activities; and (ii) it avoids the uncertainties that may arise when trying to determine whether someone meets the conditions they described as intolerable suffering in their AR for MAID. Rather, assessment of the patient focuses on whether

they are irreversibly unconscious, which relies on objectively measureable parameters and can be confirmed (or refuted) by the expert opinion of colleagues. In the Netherlands, most of the media attention, controversy, and dissent from physicians around AEDs concern cases involving patients with advanced dementia rather than those who are unconscious (DutchNews, 2017; nietstiekembijddementie.nl, 2017).

### 6.2.2 Measures to Improve ARs for MAID

Some uncertainties related to ARs for MAID are impossible to mitigate. One cannot predict exactly how a disease will progress in each individual, or how people's behaviour will change once they begin losing cognitive function. Some patients will be scared, anxious, irritable, and possibly violent, some may derive pleasure from simple activities, and some may seem happy at certain times and miserable at others (Menzel & Steinbock, 2013). Because this is unknown, it is also impossible to predict how strongly patients with a neurodegenerative condition will feel about receiving MAID as they enter the later stages of their disease (or whether they will be able to communicate their desires). One element that is easier to manage, however, is the degree to which patients consider these various possibilities when creating their AR for MAID.

#### Counsellor and Healthcare Practitioner Support for Those Drafting an AR for MAID

To facilitate the preparation of a clear document that provides the best guidance possible, it could be beneficial to provide counselling for those who wish to make an AR for MAID. Although the law in Canada and other countries is strict on requiring informed consent at the time MAID is provided, there is no such requirement for decisions made in advance directives. In countries that allow AEDs, none of the laws require patients to discuss them with a physician when they are drafted or updated (Table 5.2). If patients were encouraged to write ARs for MAID in consultation with their care team, it would allow them to receive medical advice to ensure their document was clinically relevant, to initiate discussion about their beliefs and expectations surrounding MAID, and to demonstrate that their decision to draft an AR for MAID was informed and voluntary. Working Group members also noted that such discussions are facilitated when patients are given the opportunity to communicate in their preferred language.

According to Menzel and Steinbock (2013), “[p]eople who wish to avoid severe dementia through an advance directive must inform themselves about the various stages of dementia and what life may be like in those stages,” and then write an AR for MAID that conveys “a clear sense of the stage and

affective character of the dementia to which their particular directions speak.” The authors acknowledge that this may place a burden on patients, but those who are expected to follow ARs for MAID also face a heavy burden since they must end a person’s life. Thus, it would be reasonable to expect patients to learn about their disease and take great care in preparing their AR for MAID (Menzel & Steinbock, 2013).

### 6.2.3 Measures to Improve Accessibility of ARs for MAID

If a person could not or did not wish to prepare an AR for MAID with the help of others, those responsible for implementing the request might be unaware of its existence. To deal with such a situation, Luxembourg has an official system for registering AEDs with the CNCE (Gov. of Luxembourg, 2009). There is no standardized system across Canada for recording advance directives, no standard witnessing requirements, and no federal system for registering an advance directive (Table 5.1). Only Quebec currently has a registry that contains the details of people’s advance directives (Gov. of QC, 2014). Thus, a potential safeguard might be to create a registry of ARs for MAID. Development of infrastructure to support systems-level communication, as well as clear direction on how ARs for MAID might be created, documented, and stored, could also help ensure accessibility and continuity in the application of requests across Canada.

### 6.2.4 Measures to Help with Decision-Making

Family members and healthcare practitioners who wish to respect a patient’s AR for MAID would have the difficult task of determining when that patient is ready for its implementation. No matter how much effort might be made in drafting a clear and well-informed AR for MAID, it is unlikely that every potential situation can be foreseen, especially if a person prepares the request well before implementation. Furthermore, it is impossible to know if someone has changed their mind about desiring MAID once they lose the ability to communicate. These issues would likely not arise if a person wrote a request after they were already approved for MAID (Section 4.2). In this case, they would be able to confirm their current desire for MAID themselves, and may even choose a date for the procedure.

Some literature suggests that AEDs should be viewed more as communication tools to help structure shared decision-making, rather than instructions for a healthcare practitioner (Widdershoven & Berghmans, 2001). According to Widdershoven and Berghmans (2001), choices in healthcare “are not thought out completely in advance, they are informed by our engagement in our situation and the interaction with other people.” However, de Boer *et al.* (2010b) acknowledge that this view assigns a completely different role to AEDs and

would change their legal status in the Netherlands. Regardless of the legislation that is decided upon for Canada, the view of Widdershoven and Berghmans (2001) emphasizes the fact that good written communication in an AR for MAID is only a starting point. It is also important for patients and their care team to have an ongoing dialogue to make caregivers as familiar as possible with their views in order to make decisions that best align with those values and beliefs. Although there is no way to guarantee a straightforward case in which caregivers are certain if or when they should follow through with an AR for MAID, steps could be taken to reduce the level of uncertainty.

### Continued, Frequent, and Documented Discussion of Someone's AR for MAID

One safeguard against uncertainty is frequent, documented communication that begins early and continues until the last possible moment. To share their wishes effectively, patients would need to discuss their AR for MAID while still able to clearly express themselves (and when there are no doubts about their cognitive abilities). Raising the possibility of MAID during the initial stages of their disease would allow patients to start communicating with an alternate healthcare practitioner early in the process if their current practitioner were unable to assist them. Continued, well-documented discussion could demonstrate whether someone's wish for MAID has been strong and consistent. Two legislative elements designed to help with this endeavour are found in the euthanasia laws of Belgium and Luxembourg. Both state that AEDs must be updated every five years, and that AEDs themselves, as well as any actions taken by the attending physician, must be retained in patients' medical records (Table 5.2). Although the Netherlands has guidance documents that recommend documenting, updating, and discussing AEDs (RTE, 2015c; KNMG *et al.*, 2016), these recommendations are not written into the law.

When a patient's AR for MAID becomes relevant, then by definition they have reached a point at which they no longer have the capacity to consent to MAID; however, communication with a patient at this point may still be valuable. Research ethics standards in Canada require, to the extent possible, the active participation of a patient who lacks decision-making capacity, with physical dissent precluding participation regardless of what is written in an advance directive (CIHR *et al.*, 2014). As the Working Group's analysis of Dutch cases (Section 5.6) demonstrates, even patients with advanced dementia can express their euthanasia wishes. Widdershoven and Berghmans (2001) point out that people with dementia can be involved in decision-making if they are provided with tools to help structure their communication.

### Discussion of a Person's Motivations Behind Their AR for MAID

People could provide additional guidance to their caregivers by discussing why they wish to create an AR for MAID. As discussed in Section 4.3.2, if the maker of a request articulates their fears and provides examples of particular situations they wish to avoid, others can more easily decide whether their request applies to a current situation, even if that precise situation was not described in the AR for MAID (Shaw, 2012; van Wijmen *et al.*, 2014). Open discussion would also enable people to appoint a third-party decision maker willing to follow their wishes (Section 6.2.5).

### Prospective Review as a Potential Safeguard

If family members and healthcare practitioners were having difficulty deciding whether to follow a patient's AR for MAID, it could help to involve an administrative board to conduct an independent review of the case and verify whether the conditions of the AR for MAID have been fulfilled. This would be a resource-intensive process that might not be necessary for all the scenarios discussed in this report (see especially Chapter 4), but could be helpful for more complex situations. A prospective system is not used by any of the jurisdictions that allow euthanasia except Colombia, which requires prior review of each euthanasia request by an interdisciplinary committee (composed of a physician, a lawyer, and a clinical psychologist or psychiatrist) (Gov. of Colombia, 2015).

### 6.2.5 Measures to Support Third Parties

A patient's care team would be required to implement their AR for MAID — a significant responsibility (Section 6.1.3). This sub-section discusses the importance of providing educational, procedural, and emotional support for the healthcare practitioners and loved ones who would be involved in dealing with a patient's AR for MAID.

### Professional and Emotional Support for MAID Assessors and Providers

For physicians in the Netherlands, responding to euthanasia requests is reported to be one of the most difficult tasks in medical practice (Dees *et al.*, 2013). Physicians need “exquisite skills in talking about end of life” to successfully navigate a euthanasia request, but these skills are “neither commonplace nor included in existing curricula” (Dees *et al.*, 2013). Although training in this area may not be standard procedure in the Netherlands, eligible physicians can undergo training to become a qualified SCEN physician (de Jong & van Dijk, 2017). The Support and Consultation on Euthanasia in The Netherlands (SCEN) project was implemented to help physicians during the difficult process of assessing

patients and providing euthanasia. The project was initiated by the Royal Dutch Medical Association and is funded by the government (de Jong & van Dijk, 2017). Physicians can contact SCEN physicians for general information and advice or to ask an independent consulting physician to evaluate a euthanasia request. Although an independent consultation is required to comply with the due care criteria, the consultant does not have to be a SCEN physician. Nonetheless, less than two years after the project was initiated, 85% of physicians who had performed euthanasia reported contacting SCEN for information or consultation. Most felt well supported by SCEN and the vast majority (96%) stated that they would use it again (Jansen-van der Weide *et al.*, 2004). To supplement the single consultation required for all euthanasia cases, an extra safeguard recommended by the RTE for AEDs in advanced dementia patients is consultation with a geriatrician or psychiatrist (RTE, 2015c).

In addition to clinical support, healthcare practitioners would also need legal support if ARs for MAID were allowed in Canada. In its Call for Input submission, the CMPA (2017b) emphasized that, if ARs for MAID were permitted, Canadian legislation would need to include safeguards to protect healthcare practitioners from criminal or civil prosecution if they followed a request in a reasonable manner. For example, the law might need to consider how informed consent could apply to ARs for MAID created before any diagnosis (CMPA, 2017b). Consent is considered to be informed if the nature of a proposed treatment (including its anticipated outcome and risks) and alternative treatments have been explained to a patient (Evans, 2016). It is impossible to fulfill these requirements if a person does not yet have a condition that requires treatment.

Although clinical support and legal safeguards can benefit healthcare practitioners, emotional support is also important. In some cases, the relationship that develops between a healthcare practitioner and a patient may be emotionally supportive for both parties. In a qualitative study from the Netherlands on decision-making throughout the different phases of a euthanasia request, physicians and their patients felt more supported when they built strong relationships based on a mutual understanding of the pressure on both parties (Dees *et al.*, 2013). Communication and relationships were improved when physicians “showed empathy, were clear about their boundaries and helped patients organize their thoughts and feelings,” and by patients who “were aware of the burden that providing EAS [euthanasia and assisted suicide] placed on the physician” (Dees *et al.*, 2013).

In an interview study of 16 MAID providers in Canada, participants identified increased workload as one of the challenges they face (Khoshnood *et al.*, 2018). The Ottawa Hospital, recognizing the potential need for emotional supports, has developed a resiliency program for the physicians, nurses, social workers, and other support staff involved in caring for patients who have chosen MAID (TOH, 2017). The program involves teaching the members of a patient's MAID team both individual and team strategies for preparing for, and coping during, the procedure and recovering afterwards. Key team strategies are the pre-procedure huddle, which involves a review of what each person's role will be and a check-in on any worries or concerns, and the post-procedure huddle, which includes the identification of a "buddy" on the team who will be available for check-ins and support even weeks after the procedure (TOH, 2017). If ARs for MAID were to be allowed, support programs could be an essential component of ensuring the ability of Canada's MAID assessors and providers to address the complex and difficult situations that might arise.

### Supporting Conscientious Objection Among Healthcare Practitioners

In addition to supporting healthcare practitioners who wish to provide MAID, it would be valuable to support those who conscientiously object to MAID in general; those who might be uncomfortable with ARs for MAID specifically; and those who do not have a moral objection to MAID per se, but may object to providing MAID in some individual cases. According to Kelsall (2018), safeguards for patients are included in Canada's MAID legislation, but safeguards for physicians have been implemented inconsistently across the country — and the rights of both parties deserve protection and support.

Wicclair (2011) notes several reasons why the exercise of conscience by healthcare practitioners is valuable and worth protecting. Acting against one's conscience can result in loss of moral integrity, which can cause "strong feelings of guilt, remorse, and shame as well as loss of self-respect" (Wicclair, 2011). Thus, if conscience-based refusals are not accommodated, people who value moral integrity might be discouraged from becoming healthcare practitioners. A fallout from this might be a reduction in the number of people who enter the healthcare field and a subsequent negative impact on access to healthcare. Another detrimental impact could be loss of diversity among healthcare

practitioners (Wicclair, 2011). Nonetheless, the Canadian Nurses Association acknowledges that those who conscientiously object to MAID must notify their colleagues or patients seeking MAID as soon as possible and take the necessary steps to maintain continuous, good-quality care for their clients (CNA, 2017). As long as patients communicated with their healthcare practitioner while drafting their AR for MAID, practitioners could make their views known early in the process, thus giving patients ample time to communicate with another practitioner.

### Education and Emotional Support for Families

According to the Canadian Hospice Palliative Care Association, the general population lacks an understanding of what ACP involves and the requirements and laws related to it (CHPCA, 2012). If ARs for MAID were to be permitted, a relevant safeguard could be to educate the maker of an AR and their loved ones on the complexities that might arise during the implementation process so that some may be dealt with proactively. For example, if the patient is expected to be in a care facility by the time the AR for MAID is implemented, it might be beneficial for the patient and their family to determine the level of support a facility is prepared to provide and to prepare for any obstacles that might be encountered. In Canada, hospitals are not obligated to provide MAID on their premises if they object to it (Brindley & Kerrie, 2016).

Like healthcare practitioners, families dealing with a loved one's AR for MAID would require practical and emotional support before, during, and after MAID. This could be provided by professional counsellors or other families who have been through the MAID process. Canada has a forum, called Bridge C-14, for MAID families to connect with each other and share knowledge as well as personal experiences (Bridge C-14, 2018). Bridge C-14 organizes in-person bereavement support groups and MAID family meet-ups for people who have experienced the medically assisted death of a loved one, as well as online forums where people can ask procedural questions and receive grief and stigma support (Bridge C-14, 2018). Given the complexities associated with ARs for MAID, family members might benefit from speaking to others who have navigated this process.

### 6.2.6 Measures to Identify and Prevent Patient Coercion and Abuse

Providing MAID based on an AR has the potential to generate more family conflict than providing MAID to patients who can give informed consent at the time of the procedure. According to the CMPA, disagreement among family members over a MAID request is currently a high-risk situation for healthcare practitioners (Boivin, 2018). In dealing with an AR for MAID, even well-meaning family members might disagree, but a more serious threat for patients is the potential for coercion and abuse. Someone might be compelled by another person to draft an AR for MAID for various reasons, either out of greed, malice, or unintentional bias (Section 6.1.5). This sub-section discusses some potential safeguards for mitigating issues related to patient coercion and abuse that might arise in the context of ARs for MAID.

#### Involvement of Social Workers

One way to identify and mitigate coercive influences caused by family dynamics, financial issues, or other unacceptable reasons, is to involve a social worker. A social worker could help during both the drafting and implementation of an AR for MAID. In a review of healthcare practitioner perspectives on MAID, Fujioka *et al.* (2018) emphasized the benefit of including multiple professionals (in addition to physicians) to deal with challenges that may arise during each step of the MAID process. The review pointed to several studies that “highlighted the inclusion of mental health providers and social workers, who may be better equipped to evaluate the impact of personal and contextual factors on motivations for hastened death” (Fujioka *et al.*, 2018). Although social workers are not required by law to assess MAID requests, The Ottawa Hospital opted to include a social worker as part of its team approach to MAID (Gov. of ON, 2017b). Each MAID team includes a healthcare practitioner, a second assessor, two nurses, one social worker, and administrative support (HSO, 2017). At the time of their second eligibility assessment, patients and their families meet with a social worker for an evaluation, which identifies specific supports they might need throughout the MAID process (HSO, 2017). Such an evaluation could also identify and address any concerns of abuse.

#### Designation of a Trusted SDM

People who wish to create an AR for MAID could also protect their interests by appointing a trusted SDM who will advocate for them. As mentioned in Section 5.3.2, research has shown that, in some situations, patients may feel even more comfortable relying on a trusted SDM than on their written wishes (Puchalski *et al.*, 2000). Having a single, trusted representative could protect patients from a legal standpoint, since other family members (who might not have the patient’s best interests in mind) cannot overrule the authority of an SDM. The euthanasia laws in Belgium and Luxembourg both contain a

stipulation that limits the involvement of family members to those chosen by the patient's representative. If a patient appoints one or more representatives, the AED must be discussed with them, as well as any other relatives designated by the representative (Gov. of Belgium, 2002; Gov. of Luxembourg, 2009). This could act as an extra layer of protection for patients and well-meaning family members, since the representative could prevent healthcare practitioners from discussing the AED with those who are not concerned with the patient's welfare.

If Canadian legislation regulating ARs for MAID were to be developed, it would need to be clear about the mechanism by which SDMs are named and the limits on their authority with respect to MAID. The role of SDMs in end-of-life decision-making currently varies by province/territory (Table 5.1). The Working Group acknowledges that some people might be unable to use this safeguard if they do not have someone they trust to appoint as their SDM. In this case, or in the case of suspected abuse by third parties, a province or territory's public guardian or trustee could become involved (e.g., Gov. of ON, 2018a). For those without trusted family or friends, extra support from a social worker could help protect their interests. Even for those with family or community support, a potential safeguard could be to involve an independent third party in the process to provide an outside perspective and check for patient abuse.

### **6.2.7 Measures to Ensure that an AR for MAID Is Authentic**

A key safeguard for ensuring that any MAID request (current or advance) is authentic is equal access to high-quality supportive care, so no one ever feels that MAID is the only way to address their suffering. Potential inequities in access to end-of-life care in Canada are discussed in Section 2.3. Working Group members suggest that these inequities could be amplified by the fact that MAID is a healthcare service that must be made accessible to those who request it across all jurisdictions in Canada. A similar concern has been raised by the Collège des médecins du Québec, who note that a situation could arise in which healthcare and social service resources are prioritized for those who make a MAID request, at the expense of offering resources to those who do not make a MAID request (CMQ, 2018).

For seriously ill patients in Canada, good-quality end-of-life care involves “being cared for while experiencing preservation of dignity, being treated with respect and compassion, having trust and confidence in one's doctor, and being well looked after by one's health care team” (Heyland *et al.*, 2010). In addition, patients consider effective communication to be vital. They feel it is important for healthcare practitioners to listen, deliver consistent information about their condition, and explain this information in a way patients can understand (Heyland *et al.*, 2010).

When deciding whether or not to create an AR for MAID, patients could be encouraged to think broadly about the care they might desire not only at end of life but at any point after decision-making capacity is lost. Thus, engaging in ACP could be viewed as another safeguard to prevent people from moving too quickly towards an AR for MAID, when what they truly desire is to maintain some sense of control over their own healthcare by other means. Communication is an important element of ACP and medical errors can result from ineffective communication about end-of-life preferences (Simon *et al.*, 2015; Heyland *et al.*, 2016). Some ethnic groups in Canada are less familiar with ACP than others, and members of these groups feel that efforts should be made to engage them in the process in a culturally sensitive manner by initiating discussions and providing materials in their native languages (Biondo *et al.*, 2017).

### 6.2.8 Measures to Promote Integration of ARs for MAID into the Healthcare System

This sub-section and the one that follows suggest some systems-level safeguards for ensuring that, if permitted, ARs for MAID could function as intended within the healthcare system. The safeguards discussed in this sub-section focus on improving knowledge and delivery of various healthcare components, to make people aware of the entire range of options available to them, and to make patients with a variety of conditions feel supported and valued by society.

#### Increased Engagement in ACP

Increased engagement in ACP would enhance societal awareness of the care available at end of life, and the types of healthcare decisions that people can make in advance should they lose capacity for any reason. This would help ensure that ARs for MAID were not being used to address gaps in the healthcare system that could be filled in other ways. Despite longstanding calls for improvements in end-of-life care planning, research shows that ACP (in diverse forms) remains problematic in terms of communication structures, timing, and implementation (Boot & Wilson, 2014; Kermel-Schiffman & Werner, 2017; MacKenzie *et al.*, 2018; Rietze *et al.*, 2018). Lack of public awareness and lack of engagement in ACP by healthcare practitioners have been identified as barriers to ACP (CHPCA, 2012; Rietze *et al.*, 2018). A 2014 Ipsos Reid survey found that, of 286 family physicians and general practitioners, and 200 nurses in primary care, 51% and 50%, respectively, were not comfortable with discussions of ACP (CHPCA, 2014b). An additional 24% and 32%, respectively, did not discuss ACP with their patients at all. Involvement of healthcare practitioners is key in facilitating ACP, suggesting that efforts should be made to help practitioners integrate ACP discussions into routine care (CHPCA, 2012).

### Improved Palliative Care Education

To reduce bias against people with degenerative conditions, the healthcare system (and society as a whole) must be able to support them so they can live in ways they consider meaningful. One way to address this is through better supportive and palliative care, which starts with improved education. In 2018, the CSPCP noted that although national palliative care competencies have been developed at the undergraduate level, not all medical schools in Canada have integrated them into their curricula (CSPCP, 2018). Furthermore, for those who want to specialize in palliative care, residency training programs are limited (CSPCP, 2018). Although specialized training is important, palliative care is not only performed by those who directly specialize in this field. For example, medical residents are heavily involved in end-of-life care (Schroder *et al.*, 2009), and oncology and palliative care are highly convergent in practice (Fassbender & Watanabe, 2015). In a 2015 survey of 1,114 physicians providing palliative care in Canada, only 5% identified themselves as specialists or sub-specialists in palliative medicine, while the rest identified as either family physicians focusing on palliative care (12%) or other types of physicians (83%). Among this latter group, 64% reported that they had not received any training in palliative medicine. Even among specialists, 12% reported having had no training in palliative medicine (CSPCP, 2015). Based on these results, the CSPCP called for national standards of practice to promote high-quality, safe palliative care in Canada (CSPCP, 2015).

### Rethinking Current Palliative Care Practices

Palliative care has primarily focused on cancer patients to date, but there is increasing recognition that it should also be an essential component of care for those with other potentially life-limiting or chronic conditions both within and outside hospital settings (e.g., in the community or in LTC) (Sawatzky *et al.*, 2016). Many healthcare practitioners may feel unprepared for the specificities of palliative care in diseases such as dementia (Arcand, 2015). Education for physicians and families on the continuum of care available, including a palliative approach, is essential, since the ideal decision-making process when patients can no longer participate involves collaboration between prepared physicians and informed family members (Arcand, 2015).

A *palliative approach* integrates palliative care early in the disease trajectory into both general practice and disease-specific care (Sawatzky *et al.*, 2016). Canadian studies have demonstrated the benefits of early palliative care for patients with advanced cancer and their caregivers (Zimmermann *et al.*, 2014; McDonald *et al.*, 2017). Delivering a palliative approach requires greater capacity and integration within the healthcare system to recognize and address patients' end-of-life care needs as their illnesses progress (Sawatzky *et al.*, 2016). As Sawatzky *et al.* (2016) state, “[i]t is widely acknowledged that the expertise required for a palliative approach does not lie exclusively with any particular discipline, profession or healthcare sector, and therefore inevitably requires integration into existing care models and systems in partnership with a range of healthcare providers.” Early palliative care intervention might also encourage patients who had not already engaged in ACP to begin thinking about their end-of-life treatment preferences.

### 6.2.9 Measures to Develop Effective Monitoring and Oversight Practices for MAID

If ARs for MAID were to be permitted, their impacts on society would need to be tracked effectively. This would involve, among other things, determining the populations that were creating ARs for MAID and the positive or negative effects on these populations. Monitoring involves the collection, analysis, and public dissemination of data, whereas oversight refers to the review of individual cases to determine whether legislation has been complied with (RSC, 2011). The federal government is responsible for a pan-Canadian MAID monitoring system, and local law enforcement is responsible for “investigating instances of non-compliance with the eligibility and procedural safeguards set out in the *Criminal Code*” (GC, 2018a). However, the designated recipient of MAID reports may still participate in the oversight process by identifying a need to refer a situation to the appropriate law enforcement agency (GC, 2018a). Monitoring and oversight of MAID are important safeguards that serve separate roles: collecting and reporting data helps to maintain public trust in the system, whereas expert assessment and follow-up of specific cases prevents mistakes or intentional violations of the law (RSC, 2011).

Monitoring can identify issues in MAID implementation (e.g., over- or under-representation of certain groups), but only if careful consideration is given to the way that data are collected. For example, in the Netherlands, euthanasia statistics and case studies are publicly available for researchers to analyze. However, using this information, it is not possible to determine the number of cases in which euthanasia was provided based on an AED, or to easily identify case studies that involved reliance on an AED. If Canada were to permit ARs for MAID, data would need to be collected in a manner that allows researchers to identify cases involving ARs for MAID and extract relevant information from them. The Working Group notes that, to supplement the data collected for monitoring purposes, information from qualitative studies on the perspectives of patients, family members, caregivers, SDMs, and healthcare practitioners would be important.

Canada has no review system comparable to those established in the Benelux countries. Evidence of inappropriate practice might exist in multiple venues (e.g., recorded in complaints to hospital ethics committees or the proceedings of disciplinary committees of regulatory colleges). Thus, if ARs for MAID were to be permitted, it might be challenging to aggregate Canadian data on compliance, depending on the reporting requirements. Furthermore, the Working Group notes that for healthcare practitioners dealing with ARs for MAID to be held accountable for their actions, clear avenues for reporting those who were violating the law would be needed. Self-reporting using standardized check-boxes might not be adequate to identify those who were not following the rules.

### **6.2.10 Summary of Potential Safeguards Associated with ARs for MAID**

Table 6.1 summarizes the safeguards presented in this chapter. Sections 6.2.1 to 6.2.7 discussed some potential case-specific safeguards, and the remaining two sub-sections proposed some systems-level safeguards. In Table 6.1, these case-specific safeguards are further divided into legal safeguards (those that would best address some of the legal challenges that ARs for MAID might introduce); clinical process safeguards (those that could be used to promote and optimize interactions between patients and healthcare practitioners); support for healthcare practitioners (those that could help prepare and support medical and nurse practitioners, and other staff members); and support for patients and families (those that could help strengthen communication between patients and family members, and support families in handling a loved one's AR for MAID).

Table 6.1

**Potential Safeguards Associated with ARs for MAID**

	<b>Safeguards</b>
<b>Systems-Level Safeguards</b>	<ul style="list-style-type: none"> <li>• Increased engagement in ACP</li> <li>• Improved palliative care education</li> <li>• A broader approach to palliative care</li> <li>• Effective data collection on MAID cases to enable extraction of useful information</li> <li>• An oversight mechanism with clear avenues for reporting those who are violating the law</li> </ul>
<b>Legal Safeguards</b>	<ul style="list-style-type: none"> <li>• Well-defined access criteria (e.g., only allowing ARs for MAID for irreversibly unconscious patients)</li> <li>• Additional review requirements (e.g., consultation with social workers or medical experts such as geriatricians or psychiatrists; prior review of all AR for MAID cases by a multidisciplinary committee)</li> <li>• A registry of ARs for MAID</li> <li>• Time limits on the validity of an AR for MAID (mandatory updating)</li> <li>• Modification of existing safeguards (e.g., informed consent, intolerable suffering) to make them relevant to ARs for MAID</li> <li>• Appointment of an SDM, with clear guidance and limits on the role</li> <li>• Involvement of an independent third party in assessing AR for MAID cases</li> </ul>
<b>Clinical Process Safeguards</b>	<ul style="list-style-type: none"> <li>• Counselling for people who wish to draft an AR for MAID</li> <li>• Repeated, documented discussions among patients and their care team</li> </ul>
<b>Support for Healthcare Practitioners</b>	<ul style="list-style-type: none"> <li>• Training for healthcare practitioners on legal and clinical aspects of ARs for MAID, ACP, and palliative care</li> <li>• Support services provided by specially-trained healthcare practitioners familiar with ARs for MAID</li> <li>• Emotional support for healthcare practitioners and other staff members</li> </ul>
<b>Support for Patients and Families</b>	<ul style="list-style-type: none"> <li>• Facilitation of continued discussion among people and their loved ones about their AR for MAID and the motivations behind their end-of-life wishes</li> <li>• Emotional (e.g., grief and bereavement services) and practical (e.g., legal advice, guidance from peers) support for families before, during, and after MAID</li> </ul>

### 6.3 CHAPTER SUMMARY

This chapter considers the potential impacts of prohibiting or permitting ARs for MAID, and safeguards that might be required were ARs for MAID allowed in Canada. Potential impacts may affect patients, caregivers, families, and healthcare practitioners; specific communities of people; healthcare systems; and society as a whole.

If ARs for MAID were permitted, the resulting impacts on patients, families, SDMs, and healthcare practitioners would depend on whether requests were allowed only under a well-defined set of circumstances (e.g., after patients have already been assessed as eligible for MAID) or whether they were more broadly permitted. For example, if a patient prepared an AR for MAID after they qualified for MAID, most of the potential uncertainties associated with deciding if (and when) the patient has met the conditions described as intolerable suffering would be eliminated. Many of the case-specific safeguards discussed in this chapter are directed at reducing this uncertainty; they include a range of possible laws, regulations, clinical practice guidelines, and steps that patients and families could take to make the process of following an AR for MAID clearer, safer, and less overwhelming.

Another potential impact (related to ARs for MAID and MAID in general) is that someone could write a request because they lack the health and social supports to manage their condition, and they view MAID as the only option to alleviate their end-of-life suffering. To address this impact, efforts to adequately resource the health and social care systems would need to continue, even if ARs for MAID were an available option.

At the societal level, one potential impact is the possibility that permitting ARs for MAID might send a message to people with capacity-limiting conditions that their life will have limited value at a certain point, and that MAID would become a valued option at that time. Systems-level safeguards to address this impact would involve improving knowledge and delivery of various healthcare components, thereby ensuring that people are aware of and have access to the different types of supportive care available, and that patients with a variety of conditions feel valued by society. To identify positive or negative effects on society, the impacts of ARs for MAID would need to be monitored effectively and, to address any negative outcomes, effective oversight and follow-up would be essential.

Some people might feel that the risks of ARs for MAID are too great to justify permitting them in any form, whereas others might be willing to consider the possibility of allowing them in general or under specific circumstances. These divergent views present an opportunity for further reflection and public deliberation on the specific situations in which ARs for MAID might be permitted (if any), the potential impacts that might arise in each one, and the safeguards that would be needed to address them.

# 7

## Conclusion

- **Answering the Charge**
- **Final Thoughts**

## 7 Conclusion

This report answers the charge given to the CCA by the Ministers of Health and Justice, on behalf of the Sponsors, Health Canada and the Department of Justice Canada, as they relate to ARs for MAID. As the main question of the charge requests, the report gathers available evidence to inform our understanding of ARs for MAID within the clinical, legal, cultural, ethical, and historical context in Canada. The charge also includes a number of specific questions, the answers to which are summarized below in the same order as they were addressed in the preceding chapters.

### 7.1 ANSWERING THE CHARGE

#### **How is an advance request for MAID similar to or different from advance directives for healthcare under existing provincial/territorial regimes?**

An *advance request for MAID* is a concept with no legal or clinical standing in Canada. To address the charge, the Working Group defined it as a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under circumstances outlined in the request after the person has lost decisional capacity. *Advance directives* for healthcare are directions written by a person with decision-making capacity concerning what, how, and who should make decisions on their behalf in the event that, at some time in the future, they lose capacity to make healthcare decisions.

ARs for MAID are similar to advance directives in that both document a patient's healthcare preferences and provide a mechanism to respect their autonomy after losing decision-making capacity. Because both instruments require a third party to carry out the instructions when a person cannot confirm or express their preferences, there may be uncertainty about how the person's preferences apply to a specific situation. This can place a burden on third parties responsible for making decisions based on another person's preferences and values, often without being able to consult meaningfully with that person. However, while advance directives might involve decisions that will lead to a patient's death (e.g., withholding of treatment), ARs for MAID are a request for *only* an assisted death: asking for MAID is asking a medical or nurse practitioner to take action to end one's life.

Were ARs for MAID allowed in Canada, it is unclear how their regulatory framework would differ from that of advance directives. On the one hand, healthcare regulation falls largely under provincial/territorial jurisdiction, and advance directives legislation varies considerably among provinces and territories. The extent of regulation ranges from having a registry for predefined healthcare preference options (Quebec) to not having any regulatory statute at all (Nunavut). Advance directives may include instruction directives, proxy directives, or both. Provincial and territorial legislation can define a hierarchy of potential SDMs in the event the patient has not previously identified one. In the absence of such legislation, common law regarding healthcare decision-making applies. On the other hand, MAID is an exemption to the *Criminal Code* established by federal law. Thus, unlike advance directives for healthcare, ARs for MAID would require a regulatory framework that involved both criminal law and provincial/territorial regulation.

Advance directives for healthcare indicate consent to (or refusal of) medically indicated treatment; that is, they are relevant when a treatment decision needs to be made in the care of a patient. When a healthcare practitioner is uncertain about what treatment option to follow because a patient is not able to provide consent, their preferences are unknown, and their SDM is not available, the healthcare practitioner's default action is preserving the patient's life, but avoiding irreversible treatments until consent can be obtained from the SDM. Even if a patient has an advance directive, healthcare practitioners also seek confirmation of consent from the SDM. In the context of ARs for MAID, however, the role and authority of the SDM would have to be established.

The law in Canada and other jurisdictions treats assisted death as different from other forms of medical treatment. There is disagreement in the medical and legal communities about the extent to which MAID should be seen as a standard medical practice. How a healthcare practitioner would go about evaluating the eligibility of an incapacitated person based on their AR for MAID is unclear; consideration of the transferability of eligibility criteria and safeguards as currently written would be required. The legal effectiveness of an AR for MAID as advance consent to being killed would be unprecedented in criminal law; to allow ARs for MAID would require consideration of the limits of effective consent and amendment of the *Criminal Code*.

## What are the unique considerations to be taken into account depending on when an advance request is made?

ARs for MAID might include a number of different types of practices that raise different considerations, issues, and vulnerabilities depending on the length of time between creation and implementation of a request. For example, an AR for MAID may be written by a person who has requested and been approved for MAID, to provide advance consent in case they lose capacity to reiterate consent immediately before the procedure. In this scenario, the gap of time between writing and implementing the request might only be a few days. Issues of uncertainty and vulnerability would be minimal, given the ability of the healthcare team to discuss the request with the patient and any concerns they may have prior to the patient's loss of decision-making capacity.

Additional considerations would arise as the time between writing and implementing an AR for MAID increases. For example, a request might be written after a person has been diagnosed with a disease that they believe may eventually cause intolerable suffering, because they fear they may lose capacity to consent to MAID before they might desire it. Conceivably, a person might also write an AR for MAID prior to any diagnosis or illness, perhaps because they believe that, were they to unexpectedly and permanently lose the capacity to communicate or know their surroundings, they would desire MAID. Once a person has lost capacity, it may not be possible for healthcare practitioners to have meaningful conversations with them, which could result in uncertainty about patient wishes. This uncertainty might arise from discordance between the anticipated circumstances described in the AR for MAID and the patient's current condition. Uncertainty may also arise from unclear or infrequent communication about the content of the AR for MAID or from a lack of knowledge of the patient prior to their loss of capacity. That is, uncertainty about whether the request reflects the patient's most recent values and beliefs. Such uncertainties may be reduced by strong, effective communication, such as repeated, documented discussions; long-standing, open relationships with supportive family members and healthcare practitioners; and clear articulation of the circumstances for desiring MAID, including the patient's motivations.

Under Canada's legislation, patients request MAID if *they* decide that their condition is causing them to suffer intolerably. It is unclear how an AR for MAID might address this requirement of intolerable suffering and what role the healthcare practitioner would play in assessing it. Presumably, a patient could describe circumstances in their AR for MAID that they predict would be intolerable to them and, following current legislation, the healthcare

practitioner could be satisfied the criterion of intolerable suffering was met when the patient's circumstances matched those described in the request. However, when to provide MAID would be unclear if, having met the circumstances outlined in the request, the patient did not otherwise meet all eligibility criteria or did not appear to desire MAID. An AR for MAID written prior to meeting eligibility criteria would require healthcare practitioners to assess a person's request after they have lost decision-making capacity and, potentially, the ability to communicate clearly. Healthcare practitioners who are uncomfortable with providing MAID are not obligated to do so, even when the patient meets all eligibility criteria. The Working Group notes that, in the Netherlands, uncertainties related to judging when an AED should be implemented and to evaluating others' suffering were identified as reasons why physicians are reluctant to follow AEDs in patients with advanced dementia.

Additionally, ARs for MAID require consideration of what constitutes informed consent. Informed consent is voluntary and requires the patient to have discussed anticipated outcomes and risks of proposed and alternative treatments with their healthcare team. Discussions of treatment options, potential outcomes, and motivations are unlikely to have occurred if a person does not yet have a condition that requires treatment. It may be difficult to know the voluntariness of an AR for MAID and to what extent a person was informed of their current situation when they wrote their request, particularly if they wrote it without consulting healthcare practitioners, without witnesses, or before any diagnosis.

### **What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to advance requests for MAID? What are the potential impacts on society of permitting or prohibiting advance requests for MAID?**

#### **Patients**

One implication of allowing ARs for MAID is that they would give some people who anticipate a loss of decision-making capacity the opportunity to have their previously expressed wish for MAID respected, even if they could not provide consent immediately prior to the procedure. Having some assurance that their request for MAID would be honoured could provide comfort and relieve anxiety and distress at end of life for those who make this choice.

However, permitting ARs for MAID might result in people receiving MAID who do not desire it. This could happen for several reasons: a person wrote their AR for MAID under duress or coercion; they are experiencing, or foresee experiencing, a lack of accessible and adequate support to meet their health and

social needs; or there is a biased perception about their future quality of life. It is also possible that a person may change their mind about desiring MAID but lose the ability to communicate this, or that a third-party decision maker may incorrectly interpret the AR for MAID and the person's behaviour, leading to the approval of MAID under circumstances where the patient did not desire it.

### Families, Loved Ones, and Care Providers

ARs for MAID have the potential to both alleviate and contribute to the burden of family members, loved ones, and care providers. As with patients, family members might be relieved to know that their loved one's request would be followed. However, a patient's family would also face the burden of having to decide when and how another person will die. A third party would need to decide if and when MAID is an appropriate course of action based on the contents of a patient's AR for MAID, their knowledge of the patient's wishes, and their interpretation of the patient's current state. This may be a difficult decision, particularly if it is unclear whether the patient fulfilled the conditions of their AR for MAID or whether they currently desire MAID.

### Healthcare Practitioners

Healthcare practitioners who implement ARs for MAID might feel satisfaction and relief associated with respecting a patient's choice and alleviating suffering. However, they might also feel that deliberately ending the life of someone who cannot consent to this action is an enormous responsibility. Those prepared to take on this responsibility (both MAID assessors and providers) might deal with complex requests that involve difficult judgments about a patient's decision-making capacity, their experience of suffering, and their current desire for MAID. It would be challenging for regulations and guidelines to codify all the possible circumstances under which healthcare practitioners could be certain that following an AR for MAID was legal and ethical. Thus, there might be liability concerns for those who are willing to participate in the process, as well as concerns regarding the obligations of those who conscientiously object to the process.

### Society

Allowing ARs for MAID would recognize the values of respecting patient autonomy and self-determination in Canadian society, particularly for those members of society who have lost, or anticipate losing, decision-making capacity. Some people facing future capacity loss would take comfort in knowing they would not have to endure losing the person they believe themselves to be. ARs for MAID imply a right to choose the circumstances of one's death regardless of one's ability to provide express consent at the time of death. However, there

is also concern that allowing ARs for MAID might have an impact on the way society values people with capacity loss, increasing stigma and signalling that it is acceptable to consider a life with capacity loss as one not worth living. Moreover, some have expressed concern that allowing ARs for MAID would create a society in which MAID was an appropriate alternative to providing quality and accessible care to those with capacity loss, opening the door to cost of care, bed clearing, or other considerations to explicitly or subtly enter the treatment decision-making process.

### **What are the potential risks and safeguards that might be considered related to advance requests for MAID?**

The evaluation of risks associated with permitting ARs for MAID must weigh both the nature and the likelihood of potential negative impacts. Although the Working Group did not attempt to quantify likelihood, it can comment on the evidence from the Netherlands regarding issues arising in the use of AEDs. In the Netherlands, 4 of the 16 (25%) cases involving patients with questionable decisional capacity who received euthanasia based on an AED did not comply with due care criteria. In contrast, for all euthanasia and assisted suicide cases from 2002 to 2017, the RTE found that due care criteria were not met in 0.2% of cases. Although there are some caveats in interpreting these numbers, this comparison suggests that issues are more likely to arise when consent for euthanasia is provided in an AED.

The primary risk involved in ARs for MAID is the risk that a person will receive an assisted death against their wishes. This risk is influenced by systemic and societal pressures, such as accessibility or availability of care, stigma associated with a loss of decision-making capacity, or biased assumptions about quality of life, and may manifest in either the motivations of the person writing the AR for MAID or in a third party's interpretation of the request. Case-specific pressures, including uncertainties about the AR for MAID itself, the patient's condition, and relationships among the patient, SDM, and healthcare team, also affect this risk.

Safeguards can respond to risks by reducing potential impact and/or likelihood; however, no safeguard can remove a risk entirely. Safeguards represent an effort to mitigate risk to achieve benefits for people in Canada; policy-makers will need to judge whether and where safeguards can adequately mitigate risks. No one safeguard will be sufficient on its own to mitigate all risk and, for some people, safeguards will, even collectively, be insufficient. However, a necessary

component of any set of safeguards, whether complete prohibition or otherwise, is monitoring — allowing opportunities for analyses and adaptation of policies as needed to address evolving concerns.

Healthcare system safeguards would include ensuring people in Canada who are interacting with the healthcare system are supported in their decision-making. This includes education for patients, families, and healthcare practitioners regarding clinical and legal aspects of end-of-life care, including access to quality care and support. Case-specific safeguards that may be incorporated into legislation include eligibility criteria (e.g., only allowing ARs for MAID in the case of irreversibly unconscious patients); time limits on validity of an AR for MAID; assessment requirements (e.g., expert consultation or prior review by a multidisciplinary committee); and clear guidance and limits on the role of SDMs in implementing ARs for MAID.

Legislation may also need to clarify how existing safeguards (e.g., informed consent, intolerable suffering) would apply to ARs for MAID. Safeguards that might help to optimize clinical processes include offering counselling services for patients who wish to draft an AR for MAID; involving social workers and healthcare practitioners during drafting and implementation; and having repeated, documented discussions among patients and their care team.

Other safeguards could support healthcare practitioners through the difficult clinical and legal aspects of implementing ARs for MAID by offering training, access to specially trained colleagues, and procedures to address emotional needs. Similarly, families could benefit from emotional (e.g., grief counselling) and practical (e.g., legal advice) support before, during, and after MAID. Another safeguard for families and patients could involve facilitating ongoing discussions about the patient's AR for MAID, including the motivations behind their end-of-life wishes.

Working Group members diverge in perspective on the effectiveness of potential safeguards and the assignment of an acceptable level of risk in allowing or prohibiting ARs for MAID. For example, some feel that improving the quality of and access to existing care for those who have lost decision-making capacity should take priority over permitting ARs for MAID. Some voice concern that the abandonment of a requirement for express consent immediately prior to the procedure unacceptably blurs the line between voluntary and involuntary MAID. Others can readily conceive of situations in which ARs for MAID could

be implemented with an acceptable level of risk, given the benefit of respecting the choices of people who wish to control the circumstances and timing of their death to avoid situations they consider intolerable.

### **What are the relevant gaps in domestic and international knowledge and research related to advance requests for MAID?**

No evidence exists on the use of ARs for MAID in Canada, and other countries have limited practical experience with AEDs; thus, direct evidence on the impact of allowing ARs for MAID is a significant knowledge gap. However, there is indirect evidence that can inform our understanding of allowing or prohibiting ARs for MAID from the practice of advance decision-making for healthcare in Canada and from the limited experience of AEDs in other countries.

In Canada, decision-making at end of life is largely private, confined to the bedside, and not subject to research. Few cases of conflict in end-of-life decision-making become public record, though in the clinical experience of Working Group members, a lack of recorded evidence is not evidence of a lack of conflict or uncertainty. While the accessibility and quality of healthcare range from poor to excellent in Canada, there is a documented lack of education and training in palliative care and ACP among service providers. ACP and the use of advance directives in healthcare decision-making are nonetheless encouraged, with evidence of equivocal or positive outcomes for those who participate; open and ongoing communication about one's values and preferences with family members (including a designated SDM) and healthcare practitioners is ideal.

Internationally, there has been limited use of any kind of ARs for MAID; four countries allow them, two of which only allow them when a person is irreversibly unconscious (Belgium and Luxembourg). Reporting standards vary significantly, and publicly available information ranges from statistics and case report summaries (the Netherlands), to numbers of reported cases with no additional detail (Belgium and Luxembourg), to no publicly available data (Colombia). Belgium has 322 reported cases of euthanasia by advance directive (out of 17,063 total reported cases of euthanasia and assisted suicides from 2002 to 2017). Luxembourg has one reported case of euthanasia by advance directive (out of 52 cases from 2009 to 2016). The Netherlands only allows AEDs for patients with some level of consciousness, and there are six reported cases of people registered as decisionally incompetent who received euthanasia based on their advance directive. In two of the six cases, due care criteria were not met; such cases have generated particular controversy in the Netherlands over the practice of euthanasia for patients with advanced dementia.

The practical application of AEDs, the details of professional judgments in these cases, the societal impacts of allowing AEDs, and the applicability of this evidence to the Canadian context remain significant knowledge gaps. All Working Group members underlined the importance of additional research on the experiences of those living with a loss of decision-making capacity, their families and caregivers, and their interactions with the healthcare system.

## 7.2 FINAL THOUGHTS

Removing a requirement for express consent immediately prior to the MAID procedure raises the possibility that a person might receive MAID against their wishes. Thus, the main issue with ARs for MAID is the uncertainty faced by those responsible for following the request when it comes to gauging when or whether the patient desires an assisted death. Several scenarios might fall under the Working Group's definition of ARs for MAID, influenced by timing, disease trajectory, and the circumstances of the request, each with different levels of uncertainty. ARs for MAID prepared shortly before MAID is to be provided (e.g., when a patient has already been approved for MAID or when a patient already has a potentially grievous and irremediable medical condition but is not yet suffering intolerably) would tend to involve less uncertainty than requests prepared several months or years before implementation. A judgment about whether to continue to prohibit or to permit some form of ARs for MAID would need to consider the inherent tensions among values of respecting autonomy, alleviating suffering, and protecting against vulnerabilities in light of risks and benefits specific to each scenario.

If some form of ARs for MAID were permitted in Canada, a number of potential safeguards could respond to those risks and vulnerabilities inherent in the pursuit of patient autonomy. Safeguards might operate at different levels, from ensuring a healthcare system is able to support decision-making related to ARs for MAID, to ensuring individual cases represent the voluntary and informed decisions of patients. Consensus on which situations, if any, are suitable for allowing ARs for MAID is unlikely given the differences in how factors are weighted and evidence is interpreted; situations with less uncertainty, however, are likely to find greater agreement.

While ACP and advance directives in Canada, and AEDs in other countries, can provide insight into some aspects of ARs for MAID, the inferences drawn in this report remain limited by significant knowledge gaps. This highlights the importance of further research on end-of-life practices in Canada and worldwide, including ACP, healthcare approaches, healthcare decision-making, and assisted dying.

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## APPENDIX A: ASSISTED DYING TERMINOLOGY IN JURISDICTIONS WORLDWIDE

Jurisdiction	Year Allowed	Terminology	Definition	Notes
Victoria, AUS	2019	Voluntary Assisted Dying	The administration of a voluntary assisted dying substance and includes steps reasonably related to such administration.	The Voluntary Assisted Dying Bill was passed in 2017, and will come into power June 19, 2019 at the latest.
Hawaii, USA	2019	Medical Aid in Dying	Not explicitly defined; a qualified patient may request and obtain a prescription for medication that they may self-administer to end their life in a humane and dignified manner.	The Our Care, Our Choice Act was signed into law on April 5, 2018, to take effect on January 1, 2019. Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
District of Columbia, USA	2016	Death with Dignity	The request and dispensation of covered medications to qualified patients seeking to die in a humane and peaceful manner.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
California, USA	2016	End of Life Option: Aid-in-Dying Drug	A drug determined and prescribed by a physician for a qualified individual, which the qualified individual may choose to self-administer to bring about his or her death due to a terminal disease.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
Canada	2016	Medical Assistance in Dying	The administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.	
Colorado, USA	2016	Medical Aid-in-Dying	The medical practice of a physician prescribing medical aid-in-dying medication to a qualified individual that the individual may choose to self-administer to bring about a peaceful death.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.

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Jurisdiction	Year Allowed	Terminology	Definition	Notes
Colombia	2015 (1997)	The Fundamental Right to Die with Dignity	The procedure to address the request to exercise the fundamental right to die with dignity is not explicitly defined.	The Ministry of Health and Social Protection issued a regulation on the fundamental right to die with dignity in 2015. The legal judgment that first recognized such a right in Colombia occurred in 1997.
Quebec, CAN	2014	Medical Aid In Dying	Care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death.	
Vermont, USA	2013	Patient Choice at the End of Life	Not explicitly defined; physicians are allowed to prescribe medication to a patient with a terminal condition for the purpose of hastening the patient's death if they meet certain criteria, but may not be involved in the administration of the medication.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
Montana, USA	2009	Physician Aid in Dying	Not explicitly defined; in physician aid in dying, the patient — not the physician — commits the final death-causing act by self-administering a lethal dose of medicine.	The provision of physician aid in dying is permitted through the Supreme Court of the State of Montana ruling that found a terminally ill patient's consent to physician aid in dying constitutes a statutory defense to a charge of homicide against the aiding physician when no other consent exceptions apply (Supreme Court of the State of Montana, 2009). Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.

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Jurisdiction	Year Allowed	Terminology	Definition	Notes
Luxembourg	2009	Euthanasia and Assisted Suicide	<p>Euthanasia: The act performed by a physician, which intentionally ends the life of a person at the express and voluntary request of that person.</p> <p>Assisted Suicide: a doctor intentionally helps another person to commit suicide or to provide another person with the means to that end, at the express and voluntary request of the latter.</p>	
Washington, USA	2008	Death with Dignity	Not explicitly defined; an adult who qualifies may make a written request for medication that the patient may self-administer to end his or her life in a humane and dignified manner.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.
The Netherlands	2002	Termination of Life on Request and Assisted Suicide	<p>Termination of Life on Request: Not explicitly defined.</p> <p>Assisted Suicide: Intentionally assisting in a suicide of another person or procuring for that person the means [thereto].</p>	Termination of Life on Request is commonly referred to as <i>euthanasia</i> and <i>assisted suicide</i> (EAS).
Belgium	2002	Euthanasia	Intentionally terminating life by someone other than the person concerned, at the latter's request.	The Belgium Act only refers to euthanasia; however, assisted suicide is not expressly prohibited in criminal law. Both are practised and are commonly referred to as <i>euthanasia</i> and <i>assisted suicide</i> (EAS). The Federal Control and Evaluation Commission on Euthanasia has stated that it considers assisted suicide to fall within the definition of euthanasia, and has approved cases of assisted suicide in Belgium as meeting legal requirements (Nys, 2017).
Oregon, USA	1997	Death with Dignity	Not explicitly defined; an adult who qualifies may make a written request for medication that the patient may self-administer to end his or her life in a humane and dignified manner in accordance with the law.	Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media.

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Jurisdiction	Year	Terminology	Definition	Notes
Germany	–	Assisted Suicide	Not explicitly defined; suicide is exempt from criminal punishment, as is aiding suicide. However, killing a person at the express and earnest request of the victim (“mercy killing”) is a criminal offence.	A 2015 law makes it illegal to assist in suicide for commercial intent. Relatives or other persons closely related to the patient who are only involved as non-business participants are exempt.
Switzerland	–	Assisting Suicide	Not explicitly defined.	Art. 115 of the Swiss Criminal Code (1942) states: Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty.

Sources: Constitutional Court of Colombia, 2014; GC, 2016; Gov. of Belgium, 2002; Gov. of CA, 2015; Gov. of CO, 2016; Gov. of Colombia, 2015; Gov. of DC, 2016; Gov. of Germany, 2015; Gov. of HI, 2018; Gov. of Luxembourg, 2009; Gov. of the Netherlands, 2002; Gov. of OR, 1997; Gov. of QC, 2014; Gov. of QC, 2014; Gov. of Switzerland, 1942; Gov. of Switzerland, 2017; Gov. of VT, 2013; Gov. of WA, 2009; Nys, 2017; Supreme Court of the State of Montana, 2009

Table of terminology and legal definitions used in euthanasia and assisted suicide law around the world, including notes about commonly used terms in local media and academic literature when different from the official legal terminology.

## Council of Canadian Academies' Reports of Interest

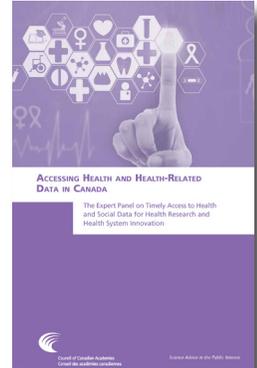
The assessment reports listed below are accessible through the CCA's website ([www.scienceadvice.ca](http://www.scienceadvice.ca)):



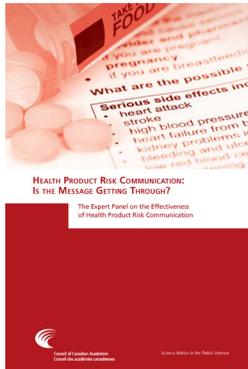
**Building on Canada's Strengths in Regenerative Medicine**  
(2017)



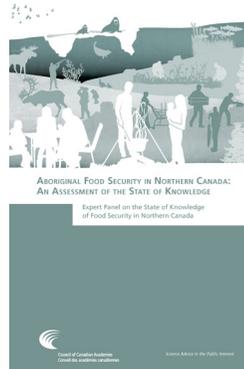
**Older Canadians on the Move**  
(2017)



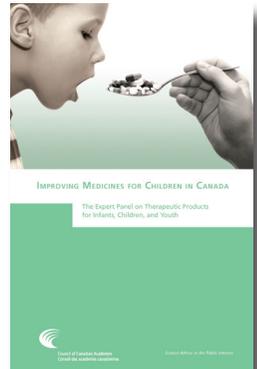
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