

# ROAD TO MERCY

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One-hour documentary premieres on CBC-TV's *FIRSTHAND*,  
Oct. 6 at 9 pm (9:30 pm NT).

83-minute feature version will premiere at festivals  
in Canada and Europe, dates TBA.

## Logline

*Road to Mercy* documents our country as it enters the farthest ethical frontier – a place where doctors are allowed to take a life and where we as a country must decide on the circumstances under which they can.

## Synopsis

*Road to Mercy* documents Canada's journey into the furthest ethical frontier – a place where doctors are allowed to take a life and where society must decide on the circumstances under which they can. Through the stories of patients who seek medically assisted death and the committed physicians who agree to help them, *Road to Mercy* chronicles Canada's first legal doctor-assisted deaths and peers into the extreme boundaries of this practice. Following stories in Canada and in Belgium, where doctor-assisted death has been legal for more than a decade, *Road to Mercy* reveals the moral and ethical quandaries at the heart of this practice during a historical moment in Canada, when both patients and doctors are struggling to identify the limits of the newly granted right to die under a broad Supreme Court of Canada decision – the first of its kind outside Europe.

After years of debate and lawsuits, medically assisted death is finally legal in Canada, following a decision by the Supreme Court to decriminalize it on February 6, 2015, in the *Carter v Canada* case. This landmark ruling allows doctors to help end their patient's life when "consenting adults determine they cannot tolerate the physical or psychological suffering brought on by a severe, incurable illness, disease or disability." The Supreme Court allowed the federal government 12 months to enact new legislation that amends the Criminal Code and upholds these fundamental human rights. When the deadline passed with no law in place, the Court granted a four-month extension during which time Canadians had access to physician-assisted dying (PAD) under the broad Supreme Court guidelines. *Road to Mercy* is a window on the historical period between February 2015 and June 2016 – after the Supreme Court ruling and before Canada's first law on medical assistance in dying (MAID).

As the new ethical frontier opens up, stakeholders – doctors, patients and Canada's foremost advocacy group, Dying With Dignity – weigh the options and test the boundaries as they put Canadians' newly granted right to die into practice. The main characters in *Road to Mercy* capture this changing legal landscape as they navigate the ethical dilemmas that must ultimately be addressed through federal legislation. The documentary follows the stories of:

- Maureen Taylor (Toronto, ON), an advocate for the right to die with dignity and the provincially appointed Co-Chair of the Ontario Advisory Panel On Physician-Assisted Dying. In this capacity, she canvassed various stakeholders – associations, medical personnel and patients – on where they stood on the issue before publishing recommendations;

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- Dr. Louis Roy (Quebec City, QC), a committed palliative care physician who provides MAID, and his terminally ill patient Danielle Lacroix, who is certain she wants MAID in the final stages of her cancer. In Quebec, the province pre-empted the Supreme Court, passing end-of-life-care legislation in 2014, which came into effect December 2015. Unlike the unanimous and broad Supreme Court decision, the Quebec legislation limits MAID to terminal patients.
- John Tuckwell (Edmonton, AB), diagnosed with ALS in 2012, his sister Cathy, and his ALS physician, Dr. Wendy Johnston. John plans on a doctor-assisted death when his quality of life has deteriorated to a state where he no longer enjoys living – something he finds difficult to pinpoint. Dr. Johnston respects his desire for PAD, but feels she can't personally offer it. She struggles to balance her professional duty to her patients and her medical code of ethics.
- Amy De Schutter (Belgium), a 29-year-old woman losing her battle with mental illness, and Dr. Lieve Thienpont, the psychiatrist handling her request for medical assistance in dying. Dr. Thienpont oversees Amy's application, as she meets with psychiatrists and other mental health professionals in the lengthy approval process to die. Belgium has the world's most progressive stance on medical assistance in dying. Belgium legalized euthanasia in 2002, going beyond terminal illness to provide medical assistance to persons with degenerative disorders and mental illness, in addition to advance directives in the event that a person becomes irreversibly unconscious. These scenarios made legal in Canada under the recent Supreme Court ruling *Carter v Canada* gives our nation the legal framework to replicate Belgian law.
- (Appears in 83-minute feature only) Jack Brown (Merrickville, ON), diagnosed with early onset dementia, and his wife Riemke Bles, turn to end of life counselor Nino Sekopet, to navigate their uncertain future. Jack and his wife are searching for a way out, one that will allow them to avoid the indignities of his disease, but they are about to learn that Canada's Supreme Court ruling does not allow PAD requests to include advance care directives.
- (Appears in 83-minute feature only) Shanaaz Gokool (Toronto, ON), CEO of Dying with Dignity Canada, who stresses the importance of advocating for advance consent for dementia patients and unforeseeable tragedies that deprive people of the ability to consent.

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## Before & After Bill C-14

*The following has been adapted from: (1) [Get the Facts: Bill C-14 And Assisted Dying Law in Canada Dying with Dignity Canada](#) (2) [CanadiEM](#), (3) [End-of-Life Law & Policy in Canada, Health Law Institute, Dalhousie University](#) and (4) [BCCLA](#).*

### **Q: Is it legal in Canada for someone to end his or her own life?**

Yes, in 1972 suicide was removed from the criminal code and it has been legal ever since.

### **Q: If Canadians already have the right to die, why do we need medically assisted dying?**

While we have the right to die, few of us have the resources to do so peacefully. Taking an over-the-counter medication or most prescription medications, even in large doses, is unlikely to lead to death and more likely to lead to irreversible damage. Accessible and effective ways of ending our lives tend to be violent. These methods are traumatic for survivors, and the individual inevitably dies alone. And, most individuals with terminal or incurable illnesses will not, at the end of their lives, be able to take their own lives in this manner.

### **Q: Before Bill C-14, what happened if an individual assisted someone else to die in Canada?**

Before Bill C-14, Section 241 of the Canadian criminal code prohibited anyone from aiding, abetting or counselling someone to suicide. Breaking the law carried a maximum sentence of 14 years in prison.

### **Q: With the passing of Bill C-14, what happens if an individual assists someone else to die in Canada?**

On June 17, 2016, new federal legislation came into force creating a regulatory framework for medical assistance in dying in Canada. Under this legislation, medical assistance in dying is legal if the eligibility criteria is met and procedural safeguards are followed.

### **Q: Are doctors able to refuse a request?**

Bill C-14 does not compel physicians to assist a patient in dying or to refer a patient to another medical practitioner. However, a number of provincial regulatory authorities have issued guidelines that strongly encourage medical practitioners who are unwilling or unable to provide MAID to refer their patients to other institutions or providers.

Bill C-14 also does not outline whether or not hospitals, hospices and institutions can refuse MAID on their premises, but some medical regulatory authorities have indicated that institutions have the right to refuse MAID within their walls.

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### Types of Medical Assistance in Dying

*The following has been adapted from: (1) [Get the Facts: Bill C-14 And Assisted Dying Law in Canada Dying with Dignity Canada](#) (2) [CanadiEM](#), (3) [End-of-Life Law & Policy in Canada, Health Law Institute, Dalhousie University](#) and (4) [BCCLA](#).*

#### **Q: What is assisted dying?**

Assisted dying is the act of intentionally killing oneself with the assistance of an authorized health care practitioner who provides the knowledge, means, or both.

#### **Q: What is euthanasia?**

Euthanasia is when an authorized health care practitioner directly administers a substance that causes death, such as an injection of a drug, at the request of the patient.

#### **Q: What is medical assistance in dying (MAID) or physician-assisted dying (PAD)?**

MAID is an umbrella term. It refers to assisted dying, euthanasia, or both.

#### **Q: What types of MAID are permitted in Canada?**

There are two types of medical assistance in dying available to Canadians. They include:

1. An authorized health care provider directly administers a substance that causes death, such as an injection of a drug (this is also known as voluntary euthanasia).
2. An authorized health care provider gives or prescribes a drug that is self-administered to cause death (this is also known as assisted dying).

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### Myths About MAID

The following has been adapted from: (1) [Get the Facts: Bill C-14 And Assisted Dying Law in Canada Dying with Dignity Canada](#) (2) [CanadiEM](#), (3) [End-of-Life Law & Policy in Canada, Health Law Institute, Dalhousie University](#) and (4) [BCCLA](#).

#### **Q: Does legalization of MAID have a negative impact on availability or quality of palliative care?**

**Reliable evidence** does not support the claim that legalization of assisted suicide has a negative impact on either availability or quality of palliative care. The evidence does not demonstrate a reduction in availability or quality of palliative care post legalization. Furthermore, availability and quality of palliative care are better in some countries that permit assisted suicide than in others that prohibit assisted suicide. For example, Belgium and the Netherlands rank higher than Canada for quality end-of-life care.

#### **Q: Does legalization of MAID put vulnerable people at heightened risk of non-voluntary or in-voluntary euthanasia?**

**Reliable evidence** supports the conclusion that legalization of assisted suicide does not put vulnerable people at heightened risk of non-voluntary or involuntary euthanasia.

Without advance consent, these individuals will most certainly be found ineligible for MAID because they will likely lose competence before they reach the required “advanced state of irreversible decline” outlined in the eligibility criteria.

The government states it will initiate an independent review to study advance consent and MAID within 180 days of the legislation receiving royal assent, but there is no guarantee that advance consent will ever be formally introduced into law. That means individuals with conditions like dementia may never qualify for MAID.

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## Supreme Court v Parliament

*The following has been adapted from: (1) [Get the Facts: Bill C-14 And Assisted Dying Law in Canada Dying with Dignity Canada](#) (2) [CanadiEM](#), (3) [End-of-Life Law & Policy in Canada, Health Law Institute, Dalhousie University](#) and (4) [BCCLA](#).*

### **Q: Under the new law, who is eligible for MAID in Canada?**

Under Bill C-14, two independent health care professionals need to evaluate an individual in order to determine whether he/she qualifies for MAID. Patients must be 18 years or older and capable of providing informed consent at the time that MAID is provided. To qualify, an individual must also meet the following four eligibility criteria:

1. Have a serious and incurable illness, disease, or disability;
2. Be in an advanced state of irreversible decline in capability;
3. Endure physical and psychological suffering that is intolerable to them; and
4. Their natural death has become reasonably foreseeable.

### **Q: How does the new law differ from the Supreme Court's Carter v Canada decision?**

Bill C-14 is much more restrictive than the Supreme Court's Carter v Canada decision.

The Supreme Court's decision made assisted dying available to any "consenting competent" adult with a "grievous and irremediable" medical condition suffering "intolerably" and "enduringly" from physical or psychological pain.

The federal government's new law includes two provisions that are much narrower in scope than the Supreme Court's decision. To qualify for assisted dying under Bill C-14, an individual must be in an advanced state of irreversible decline and their natural death must be "reasonably foreseeable" – in other words, terminally ill.

This means some individuals who were granted the right to a peaceful death by the Supreme Court will now find themselves barred from access because their deaths may not be imminent – such is the case with patients suffering from severe mental illness or non-terminal degenerative physical conditions. Other individuals, suffering from competence-eroding conditions such as dementia or a serious stroke, will also be barred if no natural end is in sight and if they are incapable of providing informed consent at the time of MAID. For many of these individuals, intolerable suffering can persist for years, which is the kind of fate the Supreme Court ruled against.

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### **Q: Are individuals suffering from a severe mental illness eligible for MAID?**

Bill C-14 doesn't explicitly ban the option of assisted dying for individuals whose sole underlying condition is a severe mental illness. But in practice, the law will exclude Canadians whose suffering results from a condition that is psychiatric at its root. Their natural deaths won't be considered "reasonably foreseeable," and thus won't satisfy the eligibility criteria set out in Bill C-14.

### **Q: Do individuals with dementia qualify for MAID?**

Under Bill C-14, advance directives for dying are not permitted. This means that while they are still of sound mind, Canadians with diagnoses of competence-eroding conditions like Alzheimer's and Huntington's disease will not be granted the right to consent to an assisted death to be carried out at a later time.

The federal government stated it will initiate an independent review to study advance consent for competence-eroding conditions within 180 days of the legislation receiving royal assent, but there is no guarantee that advance consent will ever be formally introduced into law.

### **Q: Are individuals suffering from non-terminal degenerative conditions eligible for MAID?**

Bill C-14 doesn't allow for individuals suffering from non-terminal degenerative physical conditions as Bill C-14 stipulates the condition must be terminal. This ruling is contrary to Carter v Canada.

Ten days after the federal government passed Bill C-14, Julia Lamb, a BC woman with a non-terminal degenerative muscle disease, and the BCCLA filed a constitutional challenge to the federal government's assisted dying law.

### **Q: Do mature minors qualify for MAID?**

No, only adults 18 years or older are eligible for MAID. However, the government has plans to initiate an independent review to study the legal, medical and ethical issues related to MAID for mature minors within 180 days of the legislation receiving royal assent.

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### Where Do Other Countries Stand?

*The following has been adapted from: (1) [CanadiEM](#), (2) [End-of-Life Law & Policy in Canada, Health Law Institute, Dalhousie University](#) and (3) [Dying With Dignity](#).*

#### **Q: Where is MAID or euthanasia legal in the world?**

Canada (2016), the Netherlands (2002) and Luxembourg (2009) legalized both assisted dying and euthanasia.

Assisted dying is permitted in the US states of Oregon (1997), Washington (2008), Montana (2009), Vermont (2013) and California (2015), as well as Switzerland (1942).

Columbia legalized euthanasia in 2015.

Belgium legalized euthanasia in 2002. It was initially only available to adults over the age of 18. Since February 2015, it has also been open to capable minors. Belgium's euthanasia law allows people to request euthanasia if they have unbearable psychological suffering or degenerative physical disorders. Advance directives are also permitted which allow for euthanasia once a person suffering from an illness has progressed to loss of consciousness.

*Belgium has the world's most liberal stance on dying with dignity. Carter v Canada gives our nation the legal framework to replicate Belgium law and become one of the world's most progress countries with respect to MAID.*

#### **Q: Can Canadians travel to other jurisdictions and have assisted dying?**

Only in Switzerland is it legal for non-residents to seek assisted dying. In all other jurisdictions, only residents can access the service.



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## History of Right to Die in Canada

*The following is an abridged history of the right to die in Canada adapted from the following sources. For a complete history, click on the following links: (1) [Dying with Dignity Canada](#), (2) [Osler's Bill C-14 and its Deviation from Carter 2015](#) and (4) [BCCLA](#).*

### **1972**

Suicide is legalized in Canada.

### **1983**

The Law Reform Commission of Canada recommended against legalizing or decriminalizing euthanasia. It also recommended that aiding suicide not be decriminalized where assistance has been rendered to a terminally ill person.

### **March 1991**

First bill to attempt to amend the Criminal Code (terminally ill persons) passed first reading in the House of Commons. The bill died with the prorogation of Parliament.

### **January 1992**

The Quebec Superior Court ruled in the case of Nancy B., a woman suffering from an incurable disease, that turning off her respirator at her request and letting nature take its course would not be a criminal offence.

### **September 1993**

In a five-to-four decision, the Supreme Court of Canada dismissed an appeal by Sue Rodriguez in which she challenged the validity of the Criminal Code prohibition on assisted suicide under the *Canadian Charter of Rights and Freedoms*.

### **November 1993**

The British Columbia Ministry of the Attorney General issued guidelines for Crown Counsel not to charge persons involved in cases of active euthanasia and assisted suicide.

### **February 1994**

Sue Rodriguez committed suicide with the assistance of a physician. Police investigated the death, but no criminal charge was laid.

### **June 2007**

An Ipsos Reid survey of 1,005 Canadians found that 76% of respondents supported the right to die for patients with an incurable disease (this figure has remained unchanged for 14 years). The strongest support was in Quebec with 87%, while Alberta had the lowest, with 66%.

### **December 2009**

The Quebec legislature mandated a Select Committee on Dying with Dignity to consult the public in that province on the topic of medical aid in dying.

### **April 2011**

The BC Civil Liberties Association (BCCLA) filed a court challenge against the laws that make it a criminal offense to assist seriously and incurably ill individuals to die with dignity. The challenge sought to allow seriously and incurably ill, mentally competent adults the right to receive medical assistance to hasten death under certain specific safeguards. This case is known as *Carter v Canada*.

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## **June 2011**

Gloria Taylor, suffering with ALS, filed an application with the Supreme Court of BC asking to be added as a plaintiff in the BCCLA death with dignity lawsuit filed in April 2011. In doing so, she became the lead plaintiff in *Carter v Canada*.

## **June 2012**

The BC Supreme Court ruled in favour of the BCCLA - physician-assisted deaths are protected by the *Charter of Rights and Freedoms* - and granted Taylor a personal exemption that allowed her the right to seek a physician-assisted death. The federal government appealed the ruling.

## **June 2013**

Quebec tabled right-to-die legislation in the National Assembly. The legislation would require the patient to state their intention to die in writing, have a doctor agree, and then have a second doctor confirm medically aided death is the only way to end the patient's suffering.

## **October 4, 2012**

Gloria Taylor, diagnosed with ALS, died suddenly and unexpectedly from a severe infection at the age of 64. Taylor was the only Canadian to have won the legal right to receive assistance to die, in a BC Supreme Court ruling, in June of the same year. The case was a major victory for individual rights at the end of life. After she died, the BC Court of Appeal overturned the ruling but Taylor's crusade was not in vain as *Carter v Canada* eventually made its way to the Supreme Court of Canada.

## **September 2013**

Dr. Donald Low (Canadian infectious disease specialist noted for his role in battling SARS in 2003) made a posthumous plea for death with dignity on YouTube.

## **October 10, 2013**

The BC Court of Appeal overturned the BC Supreme Court decision in the 2012 *Carter v Canada* case, stating that the Supreme Court of Canada's 1993 decision in *Rodriguez* was binding.

## **Jan 16, 2014**

The Supreme Court of Canada agreed to hear the appeal of the *Carter v Canada* case by the BCCLA.

## **March 1991 to March 2014**

A total of 19 bills to legalize medical aide in dying were introduced in Parliament over the past 25 years, all were dropped.

## **June 5, 2014**

Bill 52 - An Act Respecting End of Life Care passed into law, allowing adult residents of Québec suffering unbearably with an incurable or terminal illness to receive physician assistance at end-of-life.

## **October 15, 2014**

The Supreme Court of Canada heard an appeal of the *Carter v Canada* case by the BCCLA seeking to overturn the legal ban on doctor-assisted dying. After decades of work on the issue, and years in the lower courts, the BCCLA and their clients – the family of Kay Carter, a woman suffering from degenerative spinal stenosis and Gloria Taylor, a woman suffering from ALS - took the fight for the right to die with dignity to the highest court in the country.

## **December 10, 2015**

Quebec's physician-assisted dying law came into effect. An eleventh hour court challenge was defeated in Quebec's Superior Court on December 18 and the first physician-assisted death took place in Quebec City that same month. In Quebec, only terminally ill patients are eligible to receive a doctor's help in dying.

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## **February 6, 2015**

**Landmark Ruling:** In a unanimous decision, the Supreme Court of Canada decriminalized physician-assisted death exempting health-care providers from criminal prosecution. It also ruled that medical assistance in dying (MAID) would be available to “consenting competent” adults with “grievous and irremediable” medical conditions suffering “intolerably” and “enduringly” from physical or psychological pain. The Supreme Court allowed Parliament and the provincial legislatures 12 months to enact new legislation that upholds these fundamental human rights.

## **January 11, 2016**

The Supreme Court of Canada granted a four-month extension to its ruling suspension to allow the newly elected federal government time to consult Canadians on drafting a law to comply with the ruling and amend the Criminal Code. During this four-month window, Canadians had access to physician-assisted death (PAD) under the broad Supreme Court guidelines. The first Canadian PAD cases occurred in Quebec; the rest of the country followed suit after February 6, 2016, including a mentally ill woman and an MS patient, in Alberta and Manitoba respectively, were granted PAD.

## **June 6, 2016**

The federal government missed the deadline to pass legislation that complied with the Supreme Court's ruling. The Supreme Court's ruling becomes law. Doctors could no longer be prosecuted under the Criminal Code if they helped a patient suffering from a “grievous and irremediable medical condition”.

## **June 17, 2016**

The federal government rushed to vote through controversial Bill C-14 and it became law, effectively amending the Criminal Code. But Bill C-14's eligibility criteria is more restrictive than the original Supreme Court ruling.

Bill C-14's criteria stipulates that patients qualify only if they are "in an advanced stage of irreversible decline" from a serious and "incurable" disease, illness or disability and for whom natural death is "reasonably foreseeable." Current legislation excludes minors, individuals with non-terminal degenerative physical conditions, those suffering from severe mental illness or competence-eroding conditions such as dementia.

The Senate initially voted to amend Bill C-14 and expand the parameters around who qualifies for doctor-assisted death. But as the Supreme Court's imposed deadline to enact new legislation had passed, they ceded to the House of Commons by approving the House version of the Bill because it was “better to have a bill than no bill at all” and because excluded groups and individuals could challenge the constitutionality of Bill C-14 in court.

The federal government stated it will initiate an independent review to study advance consent for competence-eroding conditions within 180 days of the legislation receiving royal assent, but there is no guarantee that advance consent will ever be formally introduced into law.

## **June 27, 2016**

With the assistance of the BCCLA, Julia Lamb, a BC woman with spinal muscular atrophy (SMA), a non-terminal degenerative disease, filed a constitutional challenge to the federal government's assisted dying law.

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## Biographies

### **Nadine Pequenezza**

**Producer/Director/Writer, HitPlay Productions – Toronto, ON**

Nadine Pequenezza is an award-winning producer, director and writer best known for her observational films offering unique access to character-driven stories about social justice. Her multiple nominations and awards include: a Canadian Screen Award for Best Writing in a Documentary, seven CSA and Gemini nominations, a Gold Hugo from the Chicago International Film Festival, a Golden Sheaf from the Yorkton Film Festival, and a Silver Gavel Award honourable mention from the American Bar Association.

As the founder of HitPlay Productions, established in 2010, Pequenezza has produced and directed the company's feature documentary projects, including: *Up In Arms*, *Inside Disaster*, and *Raising Cassidy*. Her most recent documentary feature, *15 To Life: Kenneth's Story*, premiered in August 2014 on the award-winning PBS series POV and garnered one CSA win and three nominations: best directing, best writing and the Donald Brittain best social/political documentary.

Pequenezza is a Fledging Fellow and member of the DOC Toronto board.

### **Maureen Taylor**

**Co-Chair Of Ontario Provincial Advisory Panel On Physician-Assisted Dying – Toronto, ON**

*"What did Don Low want? He wanted a choice in how he died. He wanted to die at home with his family. He wanted to die peacefully. He's just one of many people who have suffered...Our federal government is about to enact legislation that would have allowed Don an assisted death. I don't think I'm content any more with just accomplishing this for people like Don. I realize that there are people who suffer in other ways.*

*"We ran the gamut (of opinions on MAID)...some were very in favour. Their big concern was 'I want access to this. What if I can't get access to this?'...some very vocally opposed for religious and moral objections to physician-assisted dying...I was very encouraged by what I heard...Most people are glad it's legal and now they just want to talk about how it's going to be implemented." - Maureen Taylor*

Maureen Taylor is a physician assistant in infectious diseases, medical journalist and advocate for the right to die with dignity. She was appointed Co-chair of the Ontario Provincial Advisory Panel on Physician-Assisted Dying. In this capacity, she canvassed various stakeholders – official associations, medical personnel and the general public – about where they stood on the issue before panel deliberations began. She is the widow of Dr. Donald Low, former infectious disease specialist and advocate for medically assisted dying, who succumbed to brain cancer in 2013. Taylor took up her late husband's cause – the fight for the right to die with dignity.

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### **Dr. Donald Low**

**Right to die with dignity advocate, died of natural causes 2013 – Toronto, ON**

*“I know it’s going to end. It’s never going to get better. I’m going to die. What worries me is how I’m going to die...I’m just frustrated not being able to have control over my own life.” - Dr. Donald Low*

Donald Low was a Canadian infectious disease specialist noted for his role in battling the SARS outbreak of 2003. In 2005, he took on the role of medical director of the public health laboratory of the Ontario Agency for Health Protection and Promotion. He was micro-biologist-in-chief at Mount Sinai Hospital, Toronto, from 1985 to 2013. Low was diagnosed with a brain tumour in February 2013, and died September 18, 2013, at age 68. He was an advocate of medically assisted dying and in a video published after his death, Low called for Canada to allow the right to die with dignity.

### **Dr. Louis Roy**

**Palliative care physician - Quebec City, QC**

*“My philosophy, my thinking, changed progressively. One day I told myself “Who am I to decide that you have to live up to the end of that final phase?”*

*“After I performed the first PAD, I was surprisingly ok. Everything was so clear. The patient request was so clear. The family, the team, everyone was saying, in his situation, ‘I may have done the same thing’.” - Dr. Louis Roy*

Trained as a family physician at Sherbrooke University, Louis Roy has dedicated his work over the last 20 years to the development of palliative care in Quebec City and in the province of Quebec. He chaired the Quebec Palliative Care Association from 2001 to 2006 and was the Quebec representative of the Canadian Palliative Association Board for 10 years. He co-chaired the ministerial committee for the implementation of physician-assisted dying (PAD) in 2015 with Brigitte Laflamme. He is also the Head of the CHU de Québec-Université Laval.

### **Danielle Lacroix (Is it Lacroix or LaCroix)**

**Cancer patient - Quebec City, QC**

*“I’ve made my decision. I am at my limit...I don’t want to live in the illusion that it will get better. That’s a big mistake...That’s why I won’t change my mind (about MAID), I know there is no end.” – Danielle Lacroix*

Danielle Lacroix is a 61-year-old mother with liver cancer whose was recently informed she has three months, possibly four, left to live. She is under the care of Dr. Louis Roy, a palliative doctor who also provides medical assistance in dying (MAID) to his patients. She is certain she wants assisted dying in the final stages of her illness.

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### **Cathy Tuckwell**

Caregiver and sister to ALS patient John Tuckwell - Toronto, On

*"I am sure that, unless something takes him (John Tuckwell) first, when his functionality goes, he's going to make the choice. And everyone in the family is supportive of what he wants to do." – Cathy Tuckwell*

Cathy Tuckwell is sister and a key member of a team of caregivers to John Tuckwell, diagnosed with ALS, amyotrophic lateral sclerosis, sometimes called Lou Gehrig's disease.

### **John Tuckwell**

ALS patient – Edmonton. AB

*"I'm at the stage where I spend most of my day in this chair being fed by tube and protecting what's left of my breathing. I will use my exemption when I am no longer able to communicate.*

*"This is not a shameful thing. I want other people to know that they can do this too. When I was diagnosed with ALS in October 2012, I was scared, alone, depressed and incredibly angry. Every test that ruled out other possible causes of my symptoms pitched further down that dark slope. I did consider suicide but I still had to walk my dog, still met up with friends and went to work. Then it occurred to me that I was still enjoying all that. So I decided to live well while I was still alive. I told the ALS Clinic team from the beginning that I was willing to try any intervention that could keep me doing the things I loved to do. But when I could no longer do those things or when the interventions made up the bulk of my day, I would pull the plug. I am grateful every day for the support of family and friends, my health and homecare teams, and the ALS Society of Alberta." – John Tuckwell*

John has been suffering from ALS, amyotrophic lateral sclerosis, sometimes called Lou Gehrig's disease since 2012. Previously an active person, his physical decline has been difficult on his family. He plans on a doctor-assisted death when his quality of life has deteriorated to a state where just coping with the disease takes up the bulk of his day and he no longer enjoys life. When that will be is difficult to pin down. John still manages to live on his own with the help of his sister Cathy and a supportive home-care team. His ALS doctor Wendy Johnston respects his desire for PAD but feels she can't personally offer it.

### **Dr. Wendy Johnston**

Medical Director, ALS Program – Edmonton, AB

*"He (John Tuckwell) has variously stated when this happens, I don't think I can go on and then discovered, as many do, yes he can...we call it moving of the goal posts...I respect patients' interest in and desire to complete assisted death but I can't provide it. I deal with dying patients all the time. I worry that if I were to practice assisted death, that it would essentially become something that I would think about and offer as a solution. And I think I can't do that - I can't see that as a solution. I always have to offer everything short of that." - Dr. Wendy Johnston*

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Dr. Wendy Johnston is Professor Neurology at University of Alberta and Medical Director at the University of Alberta's ALS Clinic. While at Oregon Health Sciences University (1992-2000) she established the first ALS clinic in Oregon and conducted a study on the attitudes of ALS patients and their caregivers on assisted suicide; the study was published in *The New England Journal of Medicine*. In 2000, Dr. Johnston moved to Edmonton where she re-established the ALS clinic at University of Alberta, now an interdisciplinary clinic and research programme.

### Amy De Schutter

Psychiatric patient – Belgium

*"I've been suicidal since the moment I was 13 or 14 years old. I'm almost 30 now...I have a euthanasia request. I've had several meetings with Lieve (Dr. Thienpont)...She's getting to know me better and I hope that now she really sees how much I'm suffering and she will give me the approval.*

*"I want it to happen in a dignified way...I don't want to have pain."* – Amy DeSchutter

Amy De Schutter is a 29-year-old professional woman who has been losing her battle with mental illness for more than half her life. After six diagnoses and years of treatment, nothing has relieved her psychological pain. She often tries to relieve her suffering through self-harm, cutting. She has attempted suicide more than 10 times. De Schutter's remissions are short and make her relapses even more difficult to navigate. She tells her psychiatrist she has lost the will to fight. She wants Dr. Thienpont to help end her life.

### Dr. Lieve Thienpont

Psychiatrist, University Hospital Brussels – Belgium

*"It's a tightrope just trying to motivate her (Amy) and at the same time to respect her way of feeling and seeing the whole situation. She wants euthanasia and she doesn't believe, at the moment, that she has the possibility for a better life...For some patients like Amy, it is very important to do some steps in the procedure... to see a second psychiatrist. Then they know...the request is being taken seriously and we are proceeding.*

*"We have in Belgium, 6 suicides a day, about 80-90% because of psychological suffering. People, more and more, don't want to die by suicide so they are asking for Euthanasia much earlier in their process. And I think that's a good thing.*

*"One of the most difficult things in Euthanasia is that we have to deal in subjective terms. When is it unbearable? In psychiatry, we can go on and on ...because we can always try something else...Sometimes we stretch such a long time that it ends anyway...in suicide. It's always a risk." - Dr. Lieve Thienpont*

Dr. Lieve Thienpont is a psychiatrist at University Hospital Brussels in Belgium, who specializes in assessing euthanasia requests. She is a founding member of Ulteam (established in 2011), a clinic for patients who have questions about ending their lives. She also authored a book about euthanasia and psychological suffering, *Libera Me*. Belgium, the Netherlands and Luxembourg are the only countries in Europe where psychological suffering or distress is a valid legal basis for euthanasia.

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## ROAD TO MERCY

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Dr. Thienpont is the psychiatrist handling Amy's euthanasia request. She has yet to give her approval for Amy to have a physician-assisted death. Under Belgian law Amy still needs the approval of three doctors: a referring doctor, a psychiatrist, and one other doctor. Amy has the approval of her family doctor, who has agreed to carry out her request, if she receives the other necessary approvals. Dr. Thienpont understands Amy's desire to die with dignity and avoid the brutality of suicide but wants her to take more time and exhaust other treatment options before making the final decision.

### The following characters appear only in the 83-minute feature version of *Road to Mercy*.

#### **Jack Brown**

**Dementia patient – Merrickville (near Ottawa), ON**

*"Makes me sick, thinking about it, just laying there dying."* – Jack Brown

64-year old Jack Brown has been diagnosed with early onset, genetic Alzheimer's. Doctors suspect he carries the same gene that caused his mother's early demise. He is learning that his situation is the one that confounds even the most ardent supporters of physician-assisted death. Brown and his wife are searching for a way out, one that will allow them to avoid the indignities of his disease, but they are about to learn that Canada's Supreme Court ruling does not apply to people suffering from dementia. If the right to die is to be granted to dementia patients, it will have to come from legislators.

#### **Riemke Bles**

**Wife and primary caregiver to Jack, a dementia patient – Merrickville (near Ottawa), ON**

*"Jack is losing his memory. His mother had the same illness...I remember years ago just watching his mother we used to have these conversations. And he always use to say, 'I don't want to end up like that.' With Jack, I want to be able to have a choice and he wants to be able to have a choice too. But I know once his mind is gone, it won't be able to legal anymore for him to be able to make any decisions...He knows he's losing his memory and it upsets him every day. So he takes medication to stop the agitation."*

– Riemke Bles

Reimke Bles is the wife of Jack Brown, who at age 64 suffers from early onset dementia. She is her husband's primary caregiver and supportive of his wish to die with dignity.

#### **Nino Sekopet**

**End of Life Counsellor, Dying With Dignity**

*"I get calls from people that are terminally ill or have debilitating and progressive diseases and they want to know what can we do. Control is really a big thing in end of life territory."*

– Nino Sekopet

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## ROAD TO MERCY

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Nino Sekopet is a psychotherapist with Dying With Dignity (DWD) and counselor to Jack Brown and his wife Riemke Bles. Sekopet is committed to helping them navigate their narrowing options as Jack's disease progresses. As Bill C-14 moves through parliament and advocacy groups debate whether advance directives should be included in the law, Sekopet lays out the choices that lie ahead on this heartbreaking journey.

### **Shanaaz Gokool**

**CEO, Dying with Dignity – Toronto, ON**

*“Our campaign is really going to be focused on people who have a diagnosis such as dementia, that they should be able to stipulate that they should have a physician-assisted death, should certain circumstances occur in terms of the quality of their life...Why shouldn't people who have a diagnosis also be able to stipulate with certain criteria, so for instance, if I am bedridden, unable to bathe, wash, to toilet myself, if I don't remember my family, under those conditions, I would like to have an assisted death.*”

*“The concern about dementia is so great that not trying to advocate for advance consent would be a disservice to thousands of Canadians. And it's the most critical time – our window of opportunity.”* – Shanaaz Gokool

Shanaaz Gokool is the CEO of Dying with Dignity (DWD), a national organization committed to improving quality of dying, expanding end-of-life choices and helping Canadians avoid unwanted suffering. In early 2016 she launched DWD's advocacy campaign to include the right to advance consent for assisted dying in Bill C-14. This would allow persons with a diagnosis of dementia to make an advance request for assisted death while they are still competent, that could be carried out when he or she is no longer competent. Shanaaz holds undergraduate degrees in political science and human rights and equity studies. She also has a certificate in volunteer management and fundraising. She is currently finishing her MA in international relations.

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