1. Introduction

Hello all: welcome to the dignity podcast hosted by the Canadian Institute for the Administration of Justice apart of the "In All Fairness" segment. My name is Roxana Jahani Aval. I am a rising 3rd year law student at the University of Windsor, Faculty of Law. I have the pleasure of working with the CIAJ over the summer as a Social Justice Fellow, receiving the Bruce and Nancy Elman Social Justice Fellowship in Governance and Democracy from Windsor Law.

Before beginning the discussion, I would like to take a moment to acknowledge the homeland of the Indigenous People of this place we now call Canada. I am located in the Greater Toronto Area, but would like to acknowledge Indigenous peoples from coast-to-coast-to-coast and honour the many territorial keepers of the land on which we work towards an inclusive and accessible Canada.

I would also like to take a moment to honor the advocates and colleagues that fought for and continue to fight for the rights of people with disabilities and the right to access end-of-life measures. These individuals include members from the Council of Canadians with Disabilities executive, council, and the end-of-life ethics committee. I would also like to pay my respects to the advocates that have passed away during their fight for an accessible Canada, including, Carmela Hutchinson, Alexander Peeler, Ing Wong-Ward, Sandra Carpenter, and their families; Rest in Power and thank you for all you have done for this movement.

As some may know, the journey of exploring the concept of dignity began in the fall of 2020, through Dean Reem Bahdi's Human Dignity course at Windsor Law. This work slowly shifted to publishing a three-part series on dignity with the CIAJ. Episodes 7, 8 and 9 of the "In All Fairness" segment explored whether the courts should consider the concept of dignity in decisions regarding end-of-life ethics. These episodes will be linked in the description below, or can be accessed on the CIAJ website, where you can listen to a comprehensive foundation of case law, articles and reviews of dignity, MAiD and disability. Within that series, we spoke briefly about the implications of mental health diagnosis as the sole underlying condition when accessing Medical Aid in Dying interventions (also known as MAiD).

At the end of that short conversation, I stated "this is a tricky subject and could take its own whole podcast". Well, here we are! Creating a (3-4?) part series on mental health and MAiD.

If you have not listened to the previous podcasts, have no fear! I will briefly outline the concept of dignity in itself, as well as how dignity relates to end-of-life ethics and Medical Aid in Dying.

As a result of our podcast topic, I would like to provide a trigger warning for my listeners – we will be speaking about Medical Aid in Dying that is often referred to as "assisted suicide". This topic is sensitive and may not be suitable for everyone. If conversations regarding suicide, assisted suicide, death, or mental illness are triggering, please switch off this episode and explore the other incredible content that the CIAJ has posted!

Throughout this series, we will be exploring our research topic, "whether individuals with mental illness as their sole underlying condition should be able to access Medical Aid in Dying interventions?"

To provide a short answer to my research question; I don't know. It seems a little odd for me to do months of research on the topic, to write a script and record a podcast series just to say "I don't know", but I have a reason for this.

This podcast series is created to provide perspectives for my audience to listen too, consider, ruminate and form their own opinions. I am attempting to make this podcast as neutral as possible, attempting to balance the concept of autonomous decision making and protecting the vulnerable. That being said, I think providing a short answer to my research question would be inappropriate. I do have my opinions about MAiD in relation to mental illness, but this is not about me, it's about all of you. Hence, no short answer. The answer is for you to decide.

You will notice quite a bit of discussion regarding the impact that the lack of resources and lack of access to health care have on individuals with cognitive and psychological conditions. To acknowledge the lack of resources and the lack of access to health care is to recognize that this topic is not binary, that it's not just about whether or not an individual with mental illness as their sole underlying condition should have access to MAiD. Rather, its to recognize the multitude of considerations that need to be analyzed when coming to a conclusion about our research question – one of which being the ability or inability to access resources provided by the government or other organizations. It is about considering whether individuals socio-economic condition affect their ability to access care, and how these barriers affect an individual's decision to utilize MAiD. This attempt at neutrality will have hints of commentary at the current state of affairs regarding the resources available. I will not be sharing a personal viewpoint on the topic, nor will I attempt to speak for the CIAJ, Windsor Law or any other organization or person. Instead, as I mentioned, I will be presenting a multitude of perspectives to allow you, the audience, to establish a perspective, voice and viewpoint on the issue.

Producing a roadmap for this work is vital in ensuring clarity. The roadmap will be split into 4 segments. First, we will briefly explore what the concept of dignity entails, we will define Medical Aid in Dying, explore the history of MAiD and what amendments have been enacted to MAiD legislation. Second, we will explore human dignity and its relation to mental health in general. Third, we will be exploring the intersect between human dignity, mental illness and Medical Aid in Dying legislation. Third, we will explore the current provisions and perspectives surrounding end-of-life interventions, including MAiD in relation to mental health diagnoses. Fourth, we will explore the how MAiD affects people with cognitive disorders.

In this episode, we will explore the concept of dignity and the history of medical aid in dying legislation and jurisprudence. In episode 2, we will explore what changes were made to medical aid in dying legislation from Bill C-14 to Bill C-7, as well as the connection between the concept of dignity and mental illness. Finally, in episode 3, we will explore how the concept of dignity, mental illness and medical aid in dying interrelate, as well as the impact medical aid in dying legislation has on people with cognitive conditions.

Let's jump right into the first part of our roadmap!

Episode 1:

2. **What is the concept of dignity?**

To create a simplified summary right away, I would define dignity as an interpersonal experience that encompasses the individualistic nature of decision making, autonomy, self-worth, and the right to choose, while also being cognisant of social or group values, but not explicitly linking identity or worth based on group or social categorizations. Scholar Gordon DuVal states that "Autonomy is self-rule; it is personal liberty itself."[1]

Exploring the concept of dignity depends on the lens used. We may look at dignity for an individual, group of people or in relation to how certain concepts affect humans in general. Some scholars look at dignity in the lens of reproductive technology, genetics, end-of-life ethics, and whether dignity exists for individuals before life or after death.[2] This also includes what a person's life looks like while they are alive, that they have the choice to dictate how their life is lived, and similarly, how they die.[3] Some scholars would state that dignity is too individualistic, despite it speaking directly to private or individual autonomy.[4] Other scholars state that dignity embodies free choice through autonomy and, in turn, condemns the social protection measures that are seen as failing to respect dignity since they limit free choice.[5] Some scholars believe that respect is the basis of human dignity.[6] This includes treating others with respect, being treated with respect, assuring others are given respect despite having disability, dependence or limiting capabilities and that a person is owed dignity through an intrinsic point of view, meaning that the fundamental value and moral worth of a human is based on the fact that they are of "natural kind", and deserve absolute equal, inalienable dignity.[7] In other words, a person has the right to dignity just be being alive as member of a natural kind. Erin Daly states that "the right to dignity is coming to describe what it means to be human in the modern world".[8]

In 1979 Tom Campbell wrote:

> "Dignity is something one either does or does not possess. It is an inherent, personal, indefinable concept. If a person lives with dignity, a person dies with dignity. If a person does not live with dignity, a person will not die with dignity. A dying patient in a hospital

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[1] Gordon DuVal, "Assisted Suicide and the Notion of Autonomy" (1995) 27 *Ottawa L Rev* 1 at 3 online: *CanLii* <https://canlii.ca/t/29b1>.

[2] Rory O'Connell, "The role of dignity in equality law: Lessons from Canada and South Africa" (March 21, 2008) *International Journal of Constitutional Law* 6:2 at 267-286 online: *Oxford Academic* <https://doi.org/10.1093/icon/mon004>.

[3] Tom Campbell, "Euthanasia and the Law" (1979) 17:2 *Alberta Law Review* 188 at 191 online: *CanLii* <https://canlii.ca/t/sp57>.

[4] *Supra* note 2.

[5] *Ibid*.

[6] John Vorhaus, *Giving Voice to Profound Disability: Dignity, dependence and human capabilities* (Routledge, 2015).

[7] Daniel P. Sulmasy, "Dignity, Disability, Difference, and Rights (August 28th, 2009) Philosophical Reflections on Disability at 183-198 online: Springer Link <link.springer.com/chapter/10.1007/978-90-481-2477-0_11>.

[8] Hartlee Zucker, "Dignity Rights: Courts, Constitutions, and the Worth of the Human Person, by Erin Daly" (2013) *Osgoode Hall Law Journal* 51.3 (2014) at 787 online: *Osgoode Hall* <https://digitalcommons.osgoode.yorku.ca/ohlj/vol51/iss3/5>.

> may be sustained by the steady drop from a glucose bottle, but still feel as dignified as she felt when she was healthy. Her relatives, on the other hand, may consider the scene distasteful and unseemly, and thereby rob the patient of her sense of self-worth."[9]

To capture another definition of dignity, I had the pleasure of interviewing Josh Lamers (pronouns he/him). Josh is a Black queer mad disabled child welfare survivor. As a community organizer and writer, Josh's work centres the abolition of various state apparatus in how they bring about Black death and dying, particularly child welfare. Josh is also an organizer with, Collective of Child Welfare Survivors. When I posed the question "what does the concept of dignity mean to you?", Josh presented with a definition of dignity that truly entails the intersectional nature of disability and autonomy that is not often laid out explicitly. In fact, Josh's remarks are not ones I came across throughout my research, but ultimately embodies the experience of many in our society in the modern day. Josh states that "the concept of dignity in itself is a troubling concept because … there were many communities who, in very specific ways, were never understood as humans, for example Black folx. So, when we use language of dignity, and often do attach that to legislation, we have to understand that ideas of dignity in themselves are already exclusive, because some of us were never included in your idea of human, and therefore dignity. I say that because, what some of us in the Black community... or whatever community you come from, what we consider [as] dignity might not get taken up in a legislative and/or conceptual framework when we talk about dignity. … For many of us who have lived precarious under this notion of human and current operating of dignity, that dignity for me is that we are able to breath. And it sounds so basic but, in many ways, breathing continues to come up as a literal and both metaphorical understanding of our lives, and Dr. Christina Sharpe talks about this in her book "In the Wake"; so the ability to breath and therefore construct a world in which we are able to breath until that time that we are not breathing in this physical world, that we are not living, as Dionne Brand says – "interdicted lives consistently by the systemic violence" – that we have agency, and of course that can be troubled as well, but that we are resourced."[10] I want you all to remember this quote by Josh, particularly the experiences of Black folx and Black lives in relation to dignity, as well as the conversation of dignity as being able to breath, to possess agency and to be resourced. These are topics we will look at further in the context of MAiD later on.

As we can see, there are a multitude of perspectives when it comes to dignity. Specifically, because of how diverse the concept of dignity can be, how much it can entail, all depending on who it is referring too. Within the legal community, the concept of dignity is often spoken about in the context of individual autonomy and is amplified when speaking of equality rights cases and issues. Only recently have we begun speaking to dignity in the multi-dimensional way that Josh Lamers mentioned in my interview with him – that "what we consider dignity might not get taken up in the legislative and/or conceptual framework when we talk about dignity."[11] People with intersectional identities often define dignity in a variety of ways based on their experiences with systemic discrimination and oppression, as well as the historic treatment of the group in which they identify with. We see the reality that the lives of minority groups are often excluded, either intentionally or unintentionally, from legislation and judicial decisions. This is

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[9] *Supra* note 3.

[10] Interview of Josh Lamers (June 1st, 2021).

[11] *Ibid*.

disheartening and dangerous to the dignity and autonomy of Black, Indigenous, disabled, LGBTQ+ folx.

Additionally, it is important to state that the concept of dignity is looked as a cluster concept. Where dignity encompasses multiple principles into one, principles like personal autonomy, self-respect, self-worth, physical and psychological integrity, empowerment, and the promotion of individual needs, capabilities, and merits.[12] The cluster concept is viewed as a universal set of expectations of all humans - highlighting individualistic decision making, the role of the law in facilitating the right to meaningful and informed choice, and respecting conscientious freedom.[13] In Canadian law, we utilize the cluster concept of dignity in implicit ways – specifically through the development and implication of the *Charter of Rights and Freedoms*, particularly section 7 – the right to life, liberty and security of the person, as well as section 15 – the right to equal protection and benefit under the law. In fact, an additional resource provided by the Government that was created to further understand the *Charter,* makes clear that "every individual in Canada – regardless of race, religion, national or ethnic origin, colour, sex, age or physical or mental disability – is to be treated with the same respect, dignity and consideration."[14] This is a vital addition to the explanation of section 15, as there is no explicit mention of dignity in the Canadian *Constitution Act* of 1867 or 1982.[15] Instead, we see dignity implicitly mentioned in various capacities through legislation, common law and parliamentary proceedings.[16]

When speaking about the concept of dignity in our legal system, it is arguably difficult to put our finger on how dignity affects Parliamentary and judicial decision due to the lack of an explicit mention of dignity in black letter law. Instead, the government and the judiciary are left utilizing other sources to incorporate the concept of dignity in decision making. This does not necessarily mean that the government and the judiciary are the ones incorporating a dignity analysis, but rather, legal advocates and intervenors are bringing the concept of dignity into decision making. Dignity as Epistemology is one way of incorporating dignity from advocates and interveners. Within Dean Reem Bahdi's human dignity course at Windsor Law, the principle of Dignity as Epistemology was often mentioned as a learning tool for students to understand exactly how the judiciary would incorporate a claimants lived experience into legal decisions, and in turn incorporate dignity into legal decisions. This teaching paired with Professor David Tanovich's Evidence course, where the concept of social context evidence was engrained into every lesson, I began to understand exactly how dignity entered into common law.

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[12] Reem Bahdi, *Dignity Taxonomy*, PowerPoint (Faculty of Law, University of Windsor, November 18th, 2020) at slide 3 online: Blackboard <https://blackboard.uwindsor.ca/bbcswebdav/pid-324646-dt-announcement-rid-19619704_1/courses/LAWG5830-1-R-2020F/The%20Dignity%20Course_Week%2010_Episodes%2014%20and%2015_Dignity%20Taxonomy.pptx>.

[13] Remy Debes, "Dignity: A History" (2017) *Oxford University Press* 408 online: *NDPR* <www.ndpr.nd.edu/news/dignity-a-history/>.

[14] Government of Canada, "Guide to the Canadian Charter of Rights and Freedoms" (2020) *How you rights are protected* online: *Canada.ca* <https://www.canada.ca/en/canadian-heritage/services/how-rights-protected/guide-canadian-charter-rights-freedoms.html>.

[15] *Canadian Charter of Rights and Freedoms*, s 7 & 15, Part 1 of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11, see also *The Constitution Act*, 1867, 30 & 31 Vict, c 3, <https://canlii.ca/t/ldsw>.

[16] *Supra* note 2.

Dignity as Epistemology looks to incorporate individualistic perspectives of claimants into judgements through receptive practices by judges. But this also includes stakeholders and other who can speak to the experiences and to the downfalls of the specific provision or piece of legislation. The use of social context evidence by way of intervener factum, legal research, social research and oral arguments introduce and embed the lived experience of individuals and social norms and/or realities of a group of people into legal claims and challenges. Pairing dignity as epistemology and social context evidence, assure that judges are receptive to the lived experience of claimants and incorporate social research into their decision making. In fact, we have seen this concept in use through decisions like *Mitchell v MNR and R v Le* where culturally competent and socially derived concepts guided evidence in a case.[17] Dignity as Epistemology allow judges to look at social and personal values that are introduced to the courts when trying specific cases, one of these values being dignity.[18] The extent to which judges will be receptive to the values introduced depends on the evidence that is being brought forward to provide the contextual perspectives of claimants and knowledge brought to the court by either side (and their interveners) on specific topics. When judges are receptive to considering dignity in their analysis and final decision, then personal autonomy will be considered as a vital piece of the puzzle by the judiciary through precedent, whilst also reflecting that society may be looking for the same change that an individual claimant is arguing in their case. This concept was utilized in end-of-life ethics decisions such as *Rodriguez v British Columbia*, as well as *Carter v Canada*.

Why is this important? Because the judiciary has a way in which lived experience, as well as claims of equality, dignity and autonomy can be submitted to the courts for consideration whilst utilizing the receptiveness of judges. But, does this practice exist for Parliament? Since the law does not explicitly name dignity in many pieces of legislation or court cases, the legal community must still find a way of incorporating the voices of those who are affected into the conversation. How are we explicitly bringing the concept of dignity into the creation of legislation, as we have in the judiciary? One can say that the “consultations” and “hearings” held by Parliament that introduce the voices of the community will spark conversations of dignity when mentioned by those invited to speak. But can we be sure that Parliament will listen to those voices? That the perspectives of individuals who are affected by the decisions of Parliament are actually considered in their final decisions when passing a Bill? We can argue that individuals are free to speak and provide insight into the impact legislation will have on their lives, but how can we be sure that Parliament is receptive to those voices?

Throughout the development of Bill C-14, autonomy, dignity and the right to choose were mentioned multiple times. There were countless sessions exploring the legislation, including time for questions and answers, and a multitude of perspectives were entertained. In contrast , when Bill C-7 was introduced as an amendment to Bill C-14, some advocates were unhappy with the proposed amendments and how Parliament dealt with the consultations. The specific amendments to MAiD and its impact will be explored shortly, but the point is to remark on the

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[17] David M. Tanovich, “Combatting Stereotyping & Facilitating Justice: McLachlin’s Vision for the Law of Evidence” (2019) *Controversies in the Common Law: Tracing the Contributions of Chief Justice McLachlin* at 8-9 <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=344505>.

[18] Jennifer Nedelsky, “Receptivity and Judgment” (December 20, 2011) online: *T and F* <www.tandfonline.com/doi/full/10.3402/egp.v4i4.15116?scroll=top&needAccess=true>.

use of dignity in Parliamentary decision making and legislation building. Where the voices of people who are affected by the legislation were not recognized or utilized in the way in which they were expressed. Many stakeholders who participated in the amendment consultations asked for increased safeguards and resources for palliative care, poverty, homelessness and health care, and yet Parliament took those perspectives and made amendments to legislation that the community did not necessarily agree with, all in the name of dignity. It became a backwards game, where the community originally begged the judiciary to utilize lived experience to implement dignity in legal decisions and then had to beg Parliament not to weaponize dignity as a way of expanding a law that the community did not ask for. So what gives? Is dignity used and manipulated in a way to progress a political agenda? Is it being used by the people for the people? By representatives in parliament for the people who voted them in? Or, has its meaning changed, and if so, what does that mean for people who utilize end-of-life interventions?

I will attempt to answer all of the questions I posed throughout this section, but I would like to summarize the concept of dignity and attempt to connect it to our exciting topic today. I stated earlier that the concept of dignity explores personal autonomy, personal decision making, free choice and self-preservation. This principle of autonomy and dignity is usually at the core of decisions regarding ones life, especially one's health. It is about asking, am I making this decision freely? Am I making this decision with my own needs, desires and life in mind? In fact, Shawn H.E. Herman outlined the concept well, he stated that in health law when speaking about mental illness, "The consent model, with its capacity prerequisite, protects self-determination and bodily integrity and is therefore founded on two core ethical values: human dignity and autonomy."[19] This concept provides individuals the ability to choose whether to die with dignity, but when laws prohibit individuals from making their own decisions, does it also stipulate that dignity is unachievable? Does it mean that a group of people who wish to access MAiD and cannot do so are living a life without a sense of dignity? And when I say this, I am refereeing to the sense of personal dignity. Without choice, autonomy and self-determination, do we actually possess a sense of dignity?

To bring forth one final definition of dignity to conclude this segment, I would like to refer the definition provided by Dr. John Maher during our interview. Dr. John Maher is a psychiatrist who has worked in pediatric oncology for 6 years, adult palliative care for 4 years, and only people with severe and persistent mental illness for 19 years.[20] Dr. Maher has been a support to thousands of people maneuvering the last days of their life. Dr. Maher is a member of the Assertive Community Treatment Teams, also known as (ACT) and is the Editor-in-Chief of the Journal of Ethics in Mental Health.[21] During our interview, Dr. Maher stated that "dignity means something that is worthy of respect or should be honoured, appreciated or valued. In relation to the topic before us, dignity is a central concept, [and] reality that has been both misunderstood and perverted."[22] Specifically, Dr. Maher is referring to the discussion that the term dignity is vastly differing between individuals depending on their experiences and what lens they approach

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[19] Shawn H.E. Harmon, "Consent and Conflict in Medico-Legal Decision-Making at the End of Life: A Critical Issue in the Canadian Context" (2010) *UNB Law Jour* 60:208 at 211-215 online: *UNB* <https://journals.lib.unb.ca/index.php/unblj/article/view/29203/1882524385>.
[20] Interview of Dr. John Maher (June 3rd, 2021).
[21] "John Maher" (2020) *Journal of Ethics in Mental Illness* online: *jemh.ca* <https://jemh.ca/editorial/maher.html>.
[22] *Supra* note 20.

dignity. Dr. Maher states that "dignity is how we look at someone, how we look at them with respect, how we honour the person they are, regardless of any circumstances or anything particular about the individual, that every person is worthy of dignity just by virtue of being human."[23] Interesting enough, Dr. Maher's definition of dignity reminds me of Daniel P. Sulmasy's classification of dignity that I mentioned earlier, that people deserve dignity just by being a part of the "natural kind."[24] Dr. Maher has mentioned that he does not agree with some other definitions of dignity, particularly those that state that euthanasia is the only dignified way to die.[25] But again, this critique is one of many topics we will be exploring later on.

Before further exploring the intersection between dignity, mental health and MAiD, we must understand what Medical Aid in Dying is, and where it originated from. I wanted to leave you all with this quote before moving onto our discussion on the intricacies of Medical Aid in Dying – Justice Gray of the United States Supreme Court spoke about dignity and autonomy, stating: "no right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."[26]

3. **What is Medical Aid in Dying?**

The term "Medical Aid in Dying" seems to be exclusively utilized in Canada.[27] Though, the practice of physician assisted suicide is legalized in various capacities around the world. In the United States, about 11 different states have legalized assisted death in some form – including Washington, Oregon, New Jersey, Colorado, Hawaii, Maine, Montana, Vermont, Washington, the District of Columbia and California.[28] Other countries that have legalized medically aided death or assisted suicide are Switzerland, Belgium, Colombia, the Netherlands and Luxemburg. Among these nations, there are a few that permit mental illness as an eligible condition to access MAiD, as some nations do not possess the requirement that a death be reasonably foreseeable.[29]

In Canada, when we are referring to end-of-life interventions, we are referencing palliative care[30], Medical Aid in Dying legislation[31], Bill C-14[32], Bill C-7[33] and the procedure used to die with dignity. For the purposes of this podcast series, we will be speaking specifically to Medical

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[23] *Supra* note 20.
[24] *Supra* note 7.
[25] *Supra* note 20.
[26] *Supra* note 1.
[27] Emily A Wilson, "Medical Assistance in Dying and Mental Illness: When the Illness Hindering Your Autonomy Is the Illness You Wish to Be Relieved From" (2020) 13:2 *McGill Journal of Law and Health* 1867:299 at 300-357 online: *CanLIIDocs* <https://canlii.ca/t/svqs>.
[28] *Ibid* at 309.
[29] *Ibid*.
[30] Government of Canada, "What is palliative care?" (August 27, 2019) End-of-life care online: Government of Canada < www.canada.ca/en/health-canada/services/palliative-care.html>.
[31] Medical aid in dying legislation citation Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), 1st Sess, 42nd Parl, 2016 (first reading 14 April 2016).
[32] An Act to amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying), S.C. 2016, c. 3.
[33] Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying)*, 1st Sess, 43rd Parl, 2020.

Aid in Dying legislation, Bill C-14, amendments from Bill C-7, as well as the perspectives surrounding dying with dignity in relation to mental illness. We will not be speaking to the impact of palliative care, but I will note its incredible importance in the lives of people with disabilities in Canada. If you would like to learn more about palliative care, feel free to listen to my previous podcasts on the CIAJ website.

To recount where MAiD originated from in Canada, we have to go back in history. In 1993, the infamous *Rodriguez v British Columbia* decision was released by the Supreme Court of Canada (SCC). 42-year-old Sue Rodriguez, who suffered from ALS, challenged s. 14 and s. 241 of the *Criminal Code of Canada* that prohibited the aiding or abetting of someone else's suicide.[34] Ms. Rodriguez's condition was incurable, and she did not wish to suffer for the next 2-5 years, during which time her condition would continue to deteriorate.[35] She challenged s. 14 and s. 241 of the *Criminal Code* under the *Canadian Charter of Rights and Freedoms (Charter*). Her *Charter* challenge was grounded on s 7 and s 15 claims, where s 7 assured her right to life, liberty and security of the person, and s 15 assured she would not be discriminated against on the basis of her disability. She claimed the legislation was overbroad and did not provide exceptions to the absolute prohibition of assisted suicide. Ms. Rodriguez claimed that the absolute prohibition under s. 241 of the *Criminal Code* prevented her from making autonomous decisions about her own life and prevented her from controlling her body while she's alive, a right held under s. 7's right to life, liberty and security of the person. Additionally, Ms. Rodriguez claims that the prohibition under s. 241 of the *Criminal Code* was discriminatory under s 15 of the *Charter*. Specifically, that law permitted "able-bodied persons to choose to die when they desired, but restricted disabled individuals, who were physically unable to die by non-assisted suicide, from doing so with assistance."[36] In other words, the law permits people to die by suicide if they are physically able to do so, but prevents people with disabilities, who sometimes have physical limitations, from being able to end their own lives, whilst also denying people with disabilities the ability to die with assistance.

Ms. Rodriguez's case was heard by the British Columbia Superior Court where the court ruled against the claims brought forward regarding s 7 and s 15 of the *Charter*. The court stated that the "purpose of the *Charter* is to maintain the sanctity of life" and allowing a Charter violation would be inconsistent with s 7's purpose.[37] The case was appealed to the British Columbia Supreme Court where they upheld the Superior Court's decision. The case was then appealed all the way to the SCC, where a 5:4 majority held that s. 241 of the *Criminal Code* did infringe s. 7 of the *Charter* but was saved under s. 1 of the *Charter* consistent with the principles of fundamental justice.[38] The court held that the protection of the vulnerable was the legislative purpose of s. 241, and that the law was not arbitrary in its protection against vulnerability.[39]

The court stated that "personal autonomy, at least in respect to the right to make choices concerning one's own body, control over one's physical and psychological integrity, and basic

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[34] *Supra* note 27 at 303
[35] *Ibid*.
[36] *Ibid* at 304.
[37] *Ibid* at 305.
[38] *Rodriguez v. British Columbia (Attorney General),* [1993] 3 SCR 519, 107 DLR (4th) 342 at 588, 608.
[39] *Ibid* at 601, 608.

human dignity are encompassed within security of the person, at least to the extent of freedom from criminal prohibition which interferes with these".[40] Freedom of criminal prohibition is one thing, and introducing adequate provisions to assure a qualified professional can provide end-of-life interventions is another. The court appears to have decided on the prohibition, which made the need for safeguards obsolete in this case. Adequate safeguards would prevent individuals with altered intentions in helping a person who wants to utilize assisted suicide from doing so, while protecting the dignity of the patient, and assuring that the administration of justice does not fall into disrepute. In other words, it would protect individuals from abuse and error when opting into assisted suicide. Moving forward to the year 2021, the protection against abuse and error is codified within MAiD legislation, as well as through the removal of a criminal prohibition against assisted suicide due to its unconstitutional nature of preventing professional intervention in end-of-life measures and preventing individuals from making decisions regarding their own death. Although the court in *Rodriguez* ultimately saved the provision under s 1 of the *Charter*, this case was pivotal in creating precedent on the concept of dignity in relation to MAiD and allowing for future decisions to encompass conversations of both dignity and assisted death.

Moving on to arguably the most well-known case used to understand the history of MAiD, is the 2015 Supreme Court of Canada landmark decision of *Carter v Canada*. *Carter* is the lead precedent in dying with dignity claims, end-of-life intervention and Medical Aid in Dying. As a result of the *Carter* decision, the right to life can be waived under s. 7 of the *Charter*.[41] In other words, to submit someone to suffering because of the law is depriving someone of the security and choice over the timing of their own death, it is unconstitutional.[42] The court was tasked with considering situations where a competent adult is unequivocally consenting to terminate their life, and have a grievous and irremediable medical condition.[43]

After the *Rodriguez* decision, the SCC wrote the Carter decision with the understanding the the legal and ethical circumstances regarding assisted suicide and medical aid in dying fundamentally reshaped the debate regarding end-of-life ethics and must be re-examined.[44] Scholars Rose Carter and Brandyn Rodgerson stated: "Although the law was not arbitrary, in the sense that the prohibition achieved the object of the law "to protect the vulnerable from ending their life in times of weakness," The Supreme Court found the law to be overbroad as it extended to competent, fully informed, and non-vulnerable adult patients who were prevented from ending their life with dignity."[45] And thus, *Carter* became law.

Despite summarizing the SCC's ruling in *Carter*, I would like to draw some attention to the use of dignity in the decision, including how exactly it was utilized, while also emphasizing some key points to consider in the judicial history of the *Carter* decision.

Earlier I mentioned the concept of dignity through the perspective of Dignity as Epistemology where individuals who are affected by a challenge can speak to the benefits and downfalls of the

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[40] *Ibid* at 588, 601, 608.

[41] *Carter v Canada*, 2015 SCC 5 at para 63.

[42] *Ibid* at para 25.

[43] *Supra* note 27 at 308.

[44] Rose M Carter and Brandyn Rodgerson, "Medical Assistance in Dying: Journey to Medical Self-Determination" (2018) 55:3 *Alberta Law Review* at 789 online: *CanLIIDocs* <https://canlii.ca/t/7bg>.

[45] *Ibid*.

provisions, as well as their experiences living within the current discriminatory provisions that exist. How receptive judges are depends on the evidence that is being brought forward to provide the contextual perspectives of claimants and knowledge brought to the court by either side (and their interveners) on specific topics. Dignity as Epistemology is massively important in the *Carter v Canada* decision.

The *Carter* case highlights how truly important the subjective and contextual factor of a person's medical condition, living condition, level of suffering and availability of resources are to the individual patient ability and eligibility to access MAiD. Dignity as Epistemology and social context evidence were implicitly utilized when presenting evidence. When *Carter* was making its way through the courts, Justice Smith at the Supreme Court of British Columbia heard the case. Justice Smith held that "the evidence supported the conclusion that assisted death already occurs in Canada to an unknown extent, and moving to a system of regulated assisted death would eliminate such deaths and enhance the likelihood that proper safeguards could be established."[46] This quote by Justice Smith highlights the vast importance of legislation that regulates Medical Aid in Dying for patients and people with disabilities who are disproportionately affected by the need to access MAiD. Prior to the appeal to the SCC, evidence was brought forward to the Supreme Court of British Columbia in 2012 that prompted Justice Smith to write an extensive decision for *Carter* and how it impacts individual claimant's lives but also went into an analysis regarding the grossly disproportionate nature of the ban against assisted suicide. Justice Smith stated that "the effect of the absolute prohibition on the life, liberty and security of the person interests of the plaintiffs is very severe, and is grossly disproportionate to its effect on preventing inducement of vulnerable people to commit suicide, promoting palliative care, protecting physician-patient relationships, protecting vulnerable people, and upholding the state interest in the preservation of human life."[47] Her holding speaks directly to the impact MAiD has on people with disabilities, who are more likely to utilize the legislation.

The disproportionate effect of people with disabilities utilizing MAiD was also presented in the intervener factums that were submitted to the SCC in *Carter*. Interveners in *Carter* stated that the law is arbitrary and overbroad as it stipulates an absolute prohibition against assisted dying, which in turn treats all people with disabilities as vulnerable while protecting individuals who do not need or wish to have protection, and denies people with disabilities any capacity for autonomous decisions and self-determination.[48] Justice Smith's decision and the subsequent decision from the SCC exhibits the importance of incorporating the lived experience into claims, where interveners were able to produce an analysis of the rights of people with disabilities. After the release of the decision from the SCC in *Carter*, scholars began remarking on how incredibly important the intervener factums were in this specific case. Where the interveners were able to

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[46] *Ibid* at 787.

[47] Trudo Lemmens, Heesso Kim & Elizabeth Kurz, "Why Canada's Medical Assistance in Dying Legislation Should Be C(h)arter Compliant and What It May Help to Avoid" (2017) 11:1 *McGill JL & Health* at S61 - S148 online: *CanLii* <https://canlii.ca/t/slmz> [*MAiD*], see also, Source 75 *Carter v Canada (AG),* 2012 BCSC 886 at para 1378, 261 CRR (2d) 1 [*Carter BCSC*].

[48] The Alliance of People with Disabilities Who Are Supportive of Legal Assisted Dying Society, "Factum of the Intervener – *Carter v Canada*" (August 29, 2014) Interveners to the Supreme Court of Canada online: *SCC-CSC* <www.scc-csc.ca/WebDocuments-DocumentsWeb/35591/FM130_Intervener_Alliance-of-People-with-Disabilities.pdf>.

voice the lives experience of people with disabilities, while also stating the hesitations that people with disabilities possess in this specific issue.

Now, before moving on to the next portion of this section on the history of MAiD, where we will discussing why the *Carter* decision was so important, I wanted to remark on how *Carter* addresses the topic of mental illness in relation to assisted suicide. Once reaching the SCC in 2015, the court in *Carter* did not explicitly exclude mental illness it's definition of "grievous and irremediable medical conditions".[49] Instead, the court stated that given the eligibility requirements and the nature of mental illness, individuals who seek to access MAiD with mental illness as their sole underlying condition would not meet the requirements set out.[50] Some may argue that this was purposeful, as the court in Carter stated that "there are many possible sources of error and many factors that can render a patient "decisionally vulnerable" and thereby give rise to the risk that persons without a rational and considered desire for death will in fact end up dead."[51] The court then continues on to list the potential conditions that would produce this vulnerability, such as depression or other mental illnesses, undue influence, psychological or emotional manipulation, cognitive impairment and systemic prejudice, specifically against elderly people or people with disabilities.[52] This distinction is monumental, as the court has recognized the possibility of vulnerability as a fundamental underlying consideration to deny people with mental illness from accessing MAiD. Could this recognition potentially produce constitutional challenges to MAiD in the future? Where individuals may recognize that this concept of vulnerability is pivotal in the decision to uphold a blanket prohibition against mental illness as a sole underlying condition? And in that, if a person were to challenge MAiD on the grounds that vulnerability is discriminatory to people with mental disabilities, would it be upheld by s. 1 of the *Charter*? So many questions to answer!!!

As a result of the *Carter* decision, Bill C-14 was introduced. The court provided Parliament 12-months to consult, draft and pass legislation on Medical Aid in Dying, introducing specific guidelines, safeguards and eligibility requirements that need to be satisfied before being able to access MAiD interventions. The court required Parliament to incorporate the safeguards mentioned by the court in their decision, that MAiD procedures be administered by a medical practitioner for competent adults suffering from "grievous and irremediable medical conditions that cause enduring suffering that is intolerable to the individual in the circumstances of his or her condition".[53] Additional safeguards and provisions introduced to MAiD in addition to those listed in *Carter*, include; (1) be eligible for government-funded health services in a Canadian jurisdiction, (2) be at least 18 years old, (3) have capacity to make health-related decisions, (4)

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[49] Centre for Addiction and Mental Health, "Policy Advice on Medical Assistance in Dying and Mental Illness" (October 2017) online: *CAMH.ca* <www.camh.ca/-/media/files/pdfs---public-policy-submissions/camh-position-on-mi-maid-oct2017-pdf.pdf>.

[50] Marlisa Tiedemann, "Assisted Dying in Canada After Carter v. Canada Background Paper" (2019) *Library of Parliament* 43:E online: *Gov of Canada* <https://lop.parl.ca/sites/PublicWebsite/default/en_CA/ResearchPublications/201943E#a53>.

[51] *Supra* note 41 at para 114.

[52] *Ibid*.

[53] *Ibid* at para 127.

have a grievous and irremediable medical condition, (5) make a voluntary request for medically-assisted suicide, and (6) give informed consent.[54]

Legal scholar and Professor Trudo Lemmens stated that "The law aims at balancing autonomous choice in situations of grievous and irremediable suffering with the overlapping goals of protecting people against premature choice at moments of vulnerability, but also reducing suicide (with its impact on those who die, but also their family and communities), and, importantly, the prevention of error and abuse."[55] I think this is a fair depiction of the legislation. One persistent fear surrounding the lack of adequate legislation to safeguard people who seek MAiD is the fear that individuals with terminal illnesses or deteriorating health conditions would commit suicide anyways. Where a person's persistence to die on their own terms, with control over their circumstances would end their lives in some form. Or alternatively, that they would ask someone close to them to end their lives to uphold their individualistic sense of dignity. This fear was reinforced after the SCC upheld that assisted suicide is prohibited in *Rodriguez*. Luckily, the SCC altered their decision making in *Carter* years later, allowing for legislation to be created. Additionally, there was a level of fear regarding possible error or abuse that would occur as a result of allowing MAiD to be passed. Though, the safeguards that the SCC and Parliament have implemented aid in diminishing such fears3 that health care professionals would engage in abuse or any errors.

The late constitutional law expert Peter Hogg provided a vital critique to Bill C-14, stating "it is clear that physician-assisted death includes people whose suffering is not an end-of-life condition. But, if Bill C-14 were enacted in its present form, the class of entitled persons would no longer include people whose suffering is not an end-of-life condition."[56] He predicted that a constitutional challenge would be made against Bill C-14 by an individual who satisfies the *Carter* requirements but does not suffer with an end-of-life condition, in other words, a condition that has a reasonable foreseeability of a natural death.[57] He predicted that it would come before a single judge, and the challenger will show the court three things: "(1) the order made by the Supreme Court in Carter, (2) the two decisions confirming that Carter did not require any end-of-life conditions, and (3) sections 241.2(2)(b) and (d) of Bill C-14."[58] He predicted that a judge would look at these facts and abolish the end-of-life requirement.[59] This is essentially what happened, where a constitutional challenge was made, and Parliament went ahead and created an amendment to Bill C-14 allowing conditions without a foreseeable death to become law. In doing so, Parliament essentially allowed for people who do not have a condition that would end their life in a natural way to access MAiD interventions. This would essentially allow individuals to utilize assisted suicide to end their physical pain and suffering, but also allow individuals who live with a disability, who have poor living conditions, who live in poverty, who are homeless,

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[54] Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), 1st Sess, 42nd Parl, 2016 (first reading 14 April 2016)* at cl 3 (s 241.2(1) of the Criminal Code as proposed by Bill C-14).
[55] Trudo Lemmens, "Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice" (2018) 85 SCLR 2d at 459-544.
[56] *Supra* note 44 at 798
[57] *Ibid*.
[58] *Ibid*.
[59] *Ibid*.

who are in tough socio-economic conditions to opt-into MAiD and end their suffering that may not be derived from their medical condition, but from their socio-economic living conditions.

On that note, we will be concluding this episode of the series. Episode 2 will explore what changes have been enacted to MAiD from Bill C-14 to Bill C-7, as well as how dignity and mental illness relate. To recap what we spoke about in episode 1, we looked at the various definitions of dignity, including a multitude of perspectives and opinions on how dignity relates to medical aid in dying and people with disabilities. We also explored the *Rodriguez v British Columbia* decision, as well as the ruling in *Carter v Canada*, and analyzed how these cases shaped MAiD legislation moving forward.

I want to leave you all with a quote before concluding this episode. In the article titled, "Assisted Suicide: Criminal Code or Regulatory Offence?". The authors provide an insightful phrase that really caught my attention, "While this is a difficult procedure to implement in both a practical and moral sense, dying with dignity is an important concept and relates to autonomy, beneficence, and justice, all important concepts in Canada's healthcare system".[60] But, it begs the question, what about people with mental illness who are unable to access MAiD? Are they unable to achieve autonomy, beneficence and justice under our current legislative framework for MAiD? Are they being unfairly excluded from eligibility due to the concept of consent and capacity? These are questions that are vital to the research I have conducted on this topic and we will explore these questions throughout the series.

Please feel free to share this episode and the entire series with your communities. Also, if you would like some more information on the concept of dignity, or the framework of MAiD outside of the context of mental illness, please check out episodes 9, 10 and 11 of the "In All Fairness" segment, hosted by the CIAJ, where I explore how the judiciary incorporates dignity into their decision making.

My name is Roxana Jahani Aval, until next time.

Episode 2:

4. What has changed between Bill C-14 and Bill C-7?

As I mentioned in the previous episode, Parliament was instructed to create Medical Aid in Dying legislation by the court in *Carter*. Parliament had 1 year to produce and pass the Bill. Bill C-14 made amendments to s. 241.2(1), (2), (3), and (4) of the *Criminal Code*.[61] These amended sections include information around reasonably foreseeable death, natural death, second independent medical opinions, minimum of 15-day time between the date of the request and the procedure itself, as well as the ability to withdraw the request at any time.[62]

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[60] John P. Allen, Bernard Aron, Mr. Justice Rick Libman, "Assisted Suicide: *Criminal Code* or Regulatory Offence (Part 3)" (May 2015) RegQuest.

[61] *Supra* note 54

[62] *Ibid*.

In 2016, Bill C-14 was passed and given royal assent. Bill C-14 was made to include "complex regulatory regime that permits MAID for individuals whose factual circumstances are similar to those of Ms. Taylor and Ms. Carter"[63] The legislation mentions that "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;"[64] Since Bill C-14's implementation, we have witnessed this balance between autonomy and interests of the vulnerable pan out in our society. One massive critique that the government has endured from the disability rights community is the lack of availability of resources and access to resources that would allow such a balance to be struck.

The preamble to the legislation continues, "And whereas the Government of Canada has committed to develop non-legislative measures that would support the improvement of a full range of options for end-of-life care, respect the personal convictions of health care providers and explore other situations — each having unique implications — in which a person may seek access to medical assistance in dying, namely situations giving rise to requests by mature minors, advance requests and requests where mental illness is the sole underlying medical condition;"[65] As we carry on with this podcast, I will explore whether this specific promise in the legislations preamble, was actually delivered, and whether the people who are affected by the lack of resources and the need to access MAiD truly feel about this issue, is a balance truly being struck? What does this balance mean for those with mental illness as the sole underlying condition when accessing MAiD? What about those with mental illness who cannot access, specialized treatments, specialized therapy, psychiatrists, psychologists, those who cannot afford medication, among other initiatives to better their mental illness? Where is the balance here?

To continue defining the parameters of MAiD; After Bill C-14 was passed, the Government of Canada responded to the Superior Court of Quebec's decision in *Truchon v Attorney General*, where the court found that the eligibility criteria to access MAiD was too restrictive and violated the *Charter of Rights and Freedoms*.[66] The court held that the "reasonable foreseeability of natural death" criterion outlined in end-of-life eligibility violated s. 7 of the *Charter* and s. 15 of the *Charter*.[67] The decision ultimately applies to Quebec only, since the decision was not appealed, and the court suspended the declaration of invalidity until Parliament can produce amendments based on the decision.[68]

Parliament responded to the decision in *Truchon* and created Bill C-7. The amendments from Bill C-7 came into effect on March 17th, 2021. The amendments made exceptions to the

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[63] Matthew Ponsford, "Chronic, Irremediable Depression Constituting Mental Disability: Expanding Legal Rights to Euthanasia in Canada" (2018) 82 *SCLR* 2d 237-304, see also and Source 72 *supra* note 74.
[64] An Act to amend the *Criminal Code* and to make related amendments to other Acts (*Medical Assistance in Dying*), SC 2016, c 3 [*Bill C-14*].
[65] *Ibid*.
[66] Government of Canada, "Legislative Background: Bill C-7 Government of Canada's Legislative Response to the Superior Court of Quebec *Truchon* Decision" (2020) *Department of Justice* online: <https://www.justice.gc.ca/eng/csj-sjc/pl/ad-am/c7/p1.html>, see also *Truchon c. Procureur général du Canada*, 2019 QCCS 3792.
[67] *Ibid*.
[68] *Ibid*.

requirement that a person give final consent before MAiD is performed. It provided the ability to access MAiD for those with cognitive and psychological conditions after a 2-year period as outlined in the 'Sunset Clause'. And it allows for individuals to access MAiD without a reasonable foreseeability of a natural death.

What does it mean to remove the requirement that there is reasonable foreseeability of natural death?[69] It means that individuals may access MAiD regardless of whether their death is likely to occur as a consequence of a progressive illness and does not simply refer to an individual's proximity to death (for example, from advanced or old age).[70] "'Natural death' is understood to mean that death is a likely consequence of the progressive illness for which MAiD was requested. Essentially, the amendment overrides the natural death requirement and allows an individual with permanent health issues who experience pain and suffering to access MAiD, even if their death is not within a reasonably foreseeable time, and does not have a "natural death". This specific provision was advocated by some, but also rejected by others. Some individuals believe that this is dangerous to the lives of people with disabilities, that it insinuates that people with disabilities are able to end their lives because they live with a medical condition, because they are not considered able-bodied. Others believe it to be a good thing, that it creates inclusion in the disability community, that some people are not excluded from dying with dignity if their illness is not seen as "bad enough" or "serious enough" to justify the use of MAiD. Parliament attempted to ease people's minds by incorporating the 90 days minimum time between the request to access MAiD and the time in which end-of-life interventions are delivered.[71] But even the 90-day waiting period as a safeguard has its downfalls, as Alex Schadenberg points out: "It creates a two-track law. A person who is deemed to be terminally ill would have no waiting period while a person who is not terminally ill would have a 90-day waiting period. If the bill is passed, a future court decision will likely strike down the 90-day waiting period because it would be argued that this pro-vision represents an inequality in the law."[72]

Alex Shadenberg's comments had me thinking a lot about what would have happened if the *Truchon* case went to the SCC. With what I have learnt about section 15 of the *Charter* specifically, I can see how the eligibility of reasonable foreseeability of a natural death can produce distinctions between people with disabilities that may amount to discrimination to satisfy a breach of s. 15 of the *Charter*. The requirement essentially allows those who are seriously ill to access MAiD, and those who are a little less that seriously ill who do not have a reasonable foreseeability of a natural death occurring soon from being turned away from accessing MAiD. It does not mean that the latter population is suffering any less, but rather that they have not been given a time where their death would occur, or been diagnosed with a condition where their death would occur from that specific condition. This may be subjective though, where some doctors would provide a reasonable end-date and others would not

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[69] *Ibid*.
[70] Jocelyn Downie & Jennifer A. Chandler, "Interpreting Canada's Medical Assistance in Dying Legislation (March 2018) IRPP Report at 33 online: IRPP <www.irpp.org/wp-content/uploads/2018/03/Interpreting-Canadas-Medical-Assistance-in-Dying-Legislation-MAiD.pdf>.
[71] *Supra* note 33.
[72] Alex Schadenberg, "Canada's Health Care Savings Attributed to Euthanasia" (November 2020) *The EPC Newsletter* No 222 online: *EPCC* <www.epcc.ca/wp-content/uploads/2020/10/EPC-Newsletter-222-Online.pdf>.

depending on the results of medical tests. This is where I thought, if this case had been appealed to the SCC, would it have been saved by s. 1 of the Charter? Would the SCC have prevented the amendments to reasonable foreseeability from being made in Bill C-7?

And on this thought process, another point regarding the *Truchon* case is the concept of stare decisis. Previously, commentary was made regarding *stare decisis* for the *Carter* decision after *Rodriguez* was decided, stating that "while stare decisis is fundamental to our legal system to provide certainty and order, is "is not a straitjacket that condemns the law to stasis. Trial courts may reconsider settled rulings of higher courts in two situations: (1) where a new legal issue is raised; and (2) where there is a change in the circumstances or evidence that "fundamentally shifts the parameters of the debate" in the SCC's view, both conditions were satisfied in this case."[73] It is clear that the legal issue between *Carter* and *Truchon* are fundamentally different, where one looked to the blanket prohibition against medical aid in dying, and the other looked at the safeguard implemented by *Carter* noting the reasonable foreseeability of a natural death produces a distinction between types of disabilities. Based on this new legal issue, it is likely that the SCC would have heard the *Truchon* case, and would have likely found a *Charter* breach, but would possibly have saved it under s. 1 of the *Charter*. As it stands now, it is unclear whether the amendments derived from the *Truchon* case would ultimately benefit Canadians, and whether the amendments would protect vulnerable individuals from accessing MAiD. The lack of safeguards that are implemented along with Bill C-7 have been concerning for the community. I think many would have appreciate the commentary from the SCC in this specific decision, where Parliament would have been able to get some clarification on some of the issues that were brought up in *Truchon.*

As I mentioned earlier, after *Carter*, the SCC stated that MAiD legislation must include "complex regulatory regime that permits MAID for individuals whose factual circumstances are similar to those of Ms. Taylor and Ms. Carter"[74] If the SCC had heard the *Truchon* case, and found a breach of s. 15 but saved it under s. 1, would the SCC have prevented any further changes from being made because it deters from the decision and the safeguards created by the court in that case? That MAiD was no longer being used for ALS or MS, but for long-term disabilities that people have lived with since birth that do not have a reasonable foreseeability of natural death, but do have an inherent suffering that is involved with the condition? Does this deviate? Would they have stopped such a change to MAiD legislation on these grounds? Would they have found that the reasonable foreseeability of natural death recruitment would have been saved by s. 1 of the *Charter* because of how it may affect vulnerable communities? Would they have upheld a blanket prohibition against mental illness as the sole underlying condition? Or would they have applauded such a finding in *Truchon*, that mental illness should be an eligibility requirement under MAiD? In a paper regarding Bill C-14, legal scholar Trudo Lemmens stated "The reasonably foreseeable [of a natural] death requirement that the new law embraces can be seen as a key safeguard aimed at providing the balance the Supreme Court recognized as being a crucial and acceptable goal of a strict regime. This balance under the new law is broader than the balance between respecting autonomous choice and protecting the person against her own

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[73] *Supra* note 44.

[74] *Supra* note 63, see also Department of Justice, Legislative Background: Medical Assistance in Dying (Bill C-14) Addendum (13 June 2016), online: *Gov of Canada* <www.justice.gc.ca/eng/rp-pr/other-autre/addend/index.html>.

potential vulnerability."[75] I don't think we will get answers to these questions unless an individual or group challenge the amendments from Bill C-7 and take it to the SCC, where they can address the history of the amendment and the stance of the court.

There was a question I just posed that we discussed in part but need to expand on: the concept of vulnerability, where people who live with limited resources may access MAiD not to be alleviated from their physical suffering, but to be alleviated from their socio-economic suffering. In making such an amendment, the government is allowing people with disabilities who may suffer, not due to their condition per say, but more to the lack of resources and support, to access MAiD even when their illness does not reasonably foresee a natural death approaching. Allowing individuals to access MAiD regardless of a natural death being reasonably foreseeable disproportionately affects people with disabilities who live with higher rates of unemployment, poverty, homelessness, isolation, limited resources, higher rates of mental illness. It permits people with disabilities to end their lives through assisted suicide because of the suffering they face without access to a reasonable amount of money to live off of, without the ability to find or sustain work due to inaccessible workplaces or jobs available, without the ability to socialize with others due to an inaccessible lived environment, or even due to the inability to access professional intervention for mental illness, reasons ranging from the long-wait times by the health care system to see a psychiatrist, to the lack of disposable income to regularly see a psychologist or social worker, to the long-wait times to see a psychologist or social worker, where the health-care system allot a maximum of 10 sessions for free therapy.

Heidi Janz, the chair of the Council of Canadians with Disabilities End-of-Life Ethics Committee spoke about Bill C-14 and MAiD provisions in 2020, which really caught my attention. Her words were actually my "aha" moment in understanding the true impact MAiD has on people with disabilities, that there is another argument to be had in relation to upholding people's rights. Heidi showed me that end-of-life ethics is truly a conversation about dying with dignity, or living with pain and suffering, but also that some people may begin choosing to engage in end-of-life ethics as a means of escaping their living conditions, in other words, their socio-economic circumstances.[76] I realized that individuals cannot thrive in a society that looks down on the conditions that people with disabilities live with, including impoverished communities and does little to aid individuals who live in poverty or are homeless, and a system that does not adequately combat the lack of resources available to address this fundamental issue. Catherine Frazee spoke some haunting words about Bill C-7 that highlights the darker side of the amendment, one that individuals in the disability community saw coming, she stated "It's cold comfort, I think, to be offered the choice to die when you are not offered the choice to live a dignified life — when you are not offered the basic supports and the basic dignity that we as Canadians we'd consider, I think, minimal for all members of our community,"[77] Not to jump

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[75] *Supra* note 55.

[76] Heidi Janz "Opinion: We must ensure revised assisted dying law will not threaten lives of people with disabilities", *Calgary Herald* (October 26, 2020) online: *Calgary Herald* <www.calgaryherald.com/opinion/columnists/opinion-we-must-ensure-revised-assisted-dying-law-will-not-threaten-lives-of-people-with-disabilities>.

[77] CBC Radio "'Cold comfort to be offered the choice to die' when not offered support to live, says disability advocate", *CBC News* (November 19, 2020) online: *CBC* <https://www.cbc.ca/radio/thecurrent/the-current-for-nov-19-2020-1.5807944/cold-comfort-to-be-offered-the-choice-to-die-when-not-offered-support-to-live-says-disability-advocate-1.5808541>.

around between points too much, but the comments from Heidi and Catherine had me thinking about the *Carter* decision. From what I could see throughout my research, the court in *Carter* did not intend for MAiD to be used in this way, for it to be used to end the social suffering of people in society, especially those considered to be vulnerable. The court in *Carter* produced safeguards to explicitly protect the most vulnerable in society, that it was the objective of the court and the constitution to assure the most vulnerable in society do not suffer. A littler earlier in this episode, I referred to the preamble of Bill C-14, where the legislation noted that "the Government of Canada has committed to develop non-legislative measures that would support the improvement of a full range of options for end-of-life care"[78] So, what happened? How did Parliament go from promising people with disabilities more non-legislative measures to improve end-of-life ethics, and continue to allow people with disabilities to live in poverty, with homelessness, in harmful circumstances, with fewer opportunities, the inability to find and sustain work, without adequate financial aid? How did we get here?

I also want to point out that the disproportionate rate at which people with disabilities live with poverty, homelessness, mental health struggles, unemployment and the lack of resources specifically affects some people with disabilities over others. There is a disproportionate effect on people with disabilities who are also Black, Indigenous, people of color, towards people with disabilities who are refugees or immigrants, people with disabilities without degrees or professional employment, people with disabilities who dedicate their lives to advocacy, which may be unpaid, people with disabilities who solely live off of provincial financial initiatives, etc.

These aspects of discrimination are especially present for individuals with mental illness. Despite the prevalence of mental illness, where 1 in 5 individuals experience mental illness in their lifetime[79], mental illness also disproportionately affects BIPOC people, the homeless community, people with disabilities and many others.[80] Josh Lamers states that these issues specifically affect Black folx, where he states: "When we move through time and space and place to the current moment, and were talking about the ability of the state, not only to disenfranchise lives, under resource lives, but to create a different, not new, but different method of not taking care of the world and creating new world, and of course I think this will disproportionally affect Black folx. And I think one thing that has surprised me in the conversation about MAiD and, you know, the notions about dignity and the state directing people to die, is ... that there are certain populations that were constructed to die."[81] To add onto this discussion, I bring a quote I mentioned in the previous podcast from Alex Schadenberg, where he states that "the social pressure to save money will lead to a form of social responsibility. People will be socially pressured to die."[82] There are concerns that the government has not addressed current gaps and inconsistencies that exist for people with disabilities, and passed the amendment removing the requirement of natural death being

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[78] *Supra* note 64.

[79] "Fast Facts About Mental Illness" (2013) *Canadian Mental Health Association* online: *CMHA* <https://cmha.ca/fast-facts-about-mental-illness>.

[80] Ruby Dhand, "ARTICLE: ACCESS TO JUSTICE FOR ETHNO-RACIAL PSYCHIATRIC CONSUMER/SURVIVORS IN ONTARIO" (2011) 29:127 *Windsor YB Access Just* at 127-140 online: CanLii <https://canlii.ca/t/7l8>.

[81] *Supra* note 10.

[82] *Supra* note 72.

reasonably foreseeable knowing people may access MAiD out of social desperation.[83] That Josh's comments are apropos to this point, that there is a chronic under-resourced issue that exists in our legal system and in our society, and moving to Alex's comments, that people are "socially pressured to die."[84] There is concern that the governments incompetence in dealing with the systemic contributions to poverty, homelessness, lack of resources, money and adequate healthcare are forcing people to choose to access MAiD instead of living with their current circumstances.

So, we must ask, are people accessing end-of-life interventions to end their physical suffering as a result of their illness, or as a result of their socio-economic condition? This will be spoken about in depth later on, but it is important to mention in the conversation of "What is MAiD?", since it has been a critique that many individuals in the disability community have mentioned, including Heidi, Catherine, Alex and Josh.[85]

Another addition that was made to Bill C-7 was the blanket prohibition against people with mental illness as their sole underlying condition from accessing MAiD. This blanket prohibition will end after 24-months as per the "Sunset Clause", where Parliament will raise the prohibition after creating safeguards and a framework to facilitate MAiD for those who with mental illness as their sole underlying condition.[86] In the "Summary" section of Bill C-7, "*An Act to amend the Criminal Code (medical assistance in dying)*", the enactment amends the *Criminal Code* to include section b), stating that "persons whose sole underlying medical condition is a mental illness are not eligible for medical assistance in dying;"[87]

This effectively produces a blanket prohibition against people with mental illness to access MAiD when their mental illness is their sole underlying condition, until the 24-month sunset clause period is complete. Upon conducting my research for this podcast, something Dr. Ryan Tanner wrote caught my eye, where he states: "The main concern here is whether someone with mental illness should be eligible to access assisted dying even if they do not have some other illness, that is, where mental illness is their sole underlying condition. But it is easy to see that mental illness will also (or at least seems to) complicate the issue of access to MAID even where it appears as a comorbidity with some other grievous irremediable (physical) illness. Cases of comorbidity are common because advanced physical illness is correlated with high rates of depression. For instance, about 40 percent of terminal cancer patients experience depression at some point. Most of the objections pertaining to mental illness explored below ought to function in the context of both types of case, even though comorbidity cases seem to receive much less attention."[88] Dr. Tanner is speaking of the issue of comorbidity, where this temporary blanket prohibition does not prohibit a person who has a mental illness and another medical condition

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[83] Rosanne Beuthin, Anne Bruce & Margaret Scaia, "Medical Assistance in dying (MAiD): Canadian Nurses' experiences" (July 4, 2018) Nursing Forum 53:4 online: Wiley <10.1111/nuf.12280>.
[84] *Supra* note 72.
[85] *Supra* note 76.
[86] Karandeep Sonu Gaind, "Medical assistance in dying for mental illness ignores safeguards for vulnerable people" (2021) *The Conversation* online: *Conversation* <https://theconversation.com/medical-assistance-in-dying-for-mental-illness-ignores-safeguards-for-vulnerable-people-156012>.
[87] *Supra* note 33.
[88] Ryan Tanner, "An Ethical-Legal Analysis of Medical Assistance in Dying for Those with Mental Illness" (2018) 56:1 *Alberta Law Review* at 155 online: *CanLIIDocs* <https://canlii.ca/t/2bpp>.

from accessing MAiD. In other words, a person who has mental illness and another conditions, let's continue with the example Dr. Tanner made, when he referenced cancer, where someone's cancer may not produce a reasonably foreseeable natural death (where this is no longer a requirement to access MAiD), but an individual will still be able to request MAiD so long as they meet the other requirements. But, if this individual attempt to request MAiD with their mental illness as their sole underlying condition, they will be barred from doing so until the 24-month Sunset Clause period has elapsed. Therefore, someone with mental illness alone cannot access MAiD but another individual who has cancer, even if that cancer does not produce a reasonable foreseeability of a natural death or a significant amount of pain and suffering, will be able to request MAiD because of that physical condition. At this point I need to point out that the CIAJ or I would never condone using any potential loophole to access MAiD – in pointing this out, I am attempting to highlight the risk associated when an individual attempts to override the blanket prohibition against mental illness before the Sunset Clause has elapsed, and that the lack of safeguards are potentially dangerous. Parliament has failed to produce adequate safeguards to protect the people, and instead produced a blanket prohibition in the meantime, that does not properly address the of comorbidity.

Within the amendment in Bill C-7, the government looked to initiate an independent review to understand requests where the sole underlying medical condition is that of mental illness.[89] This review will occur after the 24-month Sunset Clause is implemented. They appear to be exploring the concept of vulnerability and possible safeguards that can be implemented when the Sunset Clause is lifted to add mental illness as a sole underlying condition to MAiD eligibility, but this will likely be a longer process that requires a vast amount of research, literature, advocacy and controversy. This is a considerable amount of work to do in a short 2-year period, where consultations with psychiatrists, medical ethicists and the disability community would be foundational Many in the disability community agree with a blanket prohibition, and many disagree[90], each for a multitude of reasons, including: the right to choice, to the protection of vulnerable individuals with mental illness who may not possess adequate capacity to make such a decision, to protecting the dignity of a person's body, where they may choose to commit suicide regardless but want to die with dignity, to those who state that opening this eligibility criteria up is like opening the floodgates to other requests that may affect vulnerable populations. As you can see, there are so many perspectives that exist. Some scholars are still in the midst of writing opinions and conducting research on the matter, and by the time this podcast is published those writings will be available to explore. Until then, we will use the resources we have available and think critically about how this concept affects people with disabilities and vulnerable communities.

Please feel free to share this episode and the entire series with your communities. Also, if you would like some more information on the concept of dignity, or the framework of MAiD outside of the context of mental illness, please check out episodes 9, 10 and 11 of the "In All Fairness" segment, hosted by the CIAJ, where I explore how the judiciary incorporates dignity into their decision making.

My name is Roxana Jahani Aval, until next time.

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[89] *Supra* note 49.

[90] *Supra* note 49.

<u>Episode 3:</u>

5. <u>Why do mental illness/health and dignity relate?</u>

This section and the next section of the podcast will likely be the longest. There is just so much to say about the dignity involved in choosing death over suffering, there is a lot to say regarding the impact of choosing death for a person's loved ones, for the stigma in itself to "choose" death over "fighting" to live. And beyond all else, there are so many emotions attached to the concepts of dignity, mental illness and MAiD, but we will be discussing mental illness and dignity in relation to MAiD more specifically in a little b it.

To begin this segment, I wanted to outline what I am referring to when discussing mental illness for the purposes of MAiD. Scholar Emily Wilson highlights that "The Diagnostic and Statistical Manual of Mental Disorders (DSM) defines mental illness as a condition characterized by a disruption in regular mental functioning. Specifically, it defines mental illness as "[a] clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning." This term encompasses many different types of illnesses, including schizophrenia, borderline personality disorder, and anxiety."[91] She continues: "The National Institute of Mental Health defines a serious mental illness as "a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities." While it is possible for any mental illness condition to become classified as "serious" if it causes significant functional impairment, there are numerous types of mental illness that have been recognized as "serious", including schizophrenia, bipolar disorders, major depressive disorders, and post-traumatic stress disorders."[92]

As we can see, the definition for what constitutes a mental illness, even in reference to MAiD is very general. I would assume that any condition that satisfies the DSM-5 consideration of a mental disorder would qualify for MAiD as a mental illness that is the sole underlying condition. There is another segment to mental illness though, where cognitive disorders are considered mental disorders. Conditions such as Alzheimer's, Dementia, ALS, MS, etc. that affect a person's ability to consent and hold capacity would be considered as a mental illness as a sole underlying condition in accessing MAiD. But, more on that later.

Just to provide one more definition of dignity in relation to mental illness, I'd like to highlight autonomous decision making and the use of autonomy is health law, as I believe it is the most pivotal structure to assess when speaking about one's dignity. Specifically, for this section of the podcast, the principles of autonomy will be heavily discussed when referencing dignity. Gordon DuVal states that "the exercise of autonomy is associated with one's personal liberty or freedom -- the power to act in accordance with one's own will. More precisely, the exercise of autonomy may be seen as the authority to make voluntary and informed choices about oneself and one's life, for reasons which are one's own. Personal autonomy, at least as protection of bodily integrity, is clearly accepted to be a right, albeit one which is not absolute. A "right of autonomy" in the context of life-ending decisions has been the subject of much discussion. I will argue that

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[91] *Supra* note 27 at 301-302.

[92] *Ibid* at 313.

very little about the right of autonomy is as straightforward as it appears, and that talk of rights, while not wholly inappropriate, is not so central to these questions as might be supposed."[93]

When speaking of dignity and mental illness outside of the context of MAiD, we must identify the importance of rights and choice in mental health law. Specifically, when referring to hospitalization, sometimes without their consent, under the guise of safety, there holds a significant power imbalance between patient and practitioner. An individual may lose their ability to make autonomous decisions regarding their health or wellbeing while under care, all governed by provincial mental health legislation that allows for such autonomous decisions to be stripped away.[94] "The *Mental Health Act* is replete with procedural safeguards. The safeguards have been implemented in recognition of the fact that a patient who is detained under the authority of the *Mental Health Act* or who loses control over his or her own treatment or assets has been deprived of their liberty, autonomy or right to self-determination no less than an individual who has been imprisoned."[95] On this point, scholar Lora Patton adds to the remarks from *Re Koch*, stating: "When the state attempts to change our legal status within society, that process "must be cloaked with appropriate safeguards and capable of withstanding rigorous review ... The dignity of the individual is at stake", where she draws from the *Re Koch* decision to establish the importance of procedural safeguards surrounding mental illness.[96] Lora Patton continues: "Such is the case particularly where vulnerable persons are involved, as noted by the Ontario Court of Appeal more than fifteen years ago in *Fleming* v. *Reid*: Mentally ill persons are not to be stigmatized because of the nature of their illness or disability; nor should they be treated as persons of lesser status or dignity. Their right to personal autonomy and self-determination is no less significant, and is entitled to no less protection, than that of competent persons suffering from physical ailments."[97]

So, what does this tell us about the function of dignity in the law surrounding mental illness? It shows us that people with mental illness have historically been subjected to the stripping of their rights and dignity in the name of legislation and under the guide of safety. People with mental illness have supposedly been given safeguards to protect them, but it has amounted to the removal of many fundamental rights, such as one's liberty. As we've seen, the removal of those rights is synonymous to that of imprisonment.[98] People with mental illness have not been given fair or just treatment in our legal system, and their sense of autonomy is often forcibly removed. To be frank, some individuals in society have been more adversely affected than others, such as Black, Indigenous, people of color, disabled folx, those in the LGBTQ+ community, where these folx are more often under-resourced and overly legislated against.[99] That being said, it is that much more important to assure that an individual possesses autonomy in situations of life and

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[93] *Supra* note 1 at 6.

[94] Lora Patton, "'These Regulation Aren't Just Here to Annoy You:' The Myth of Statutory Safeguards, Patient Rights and Charter Values in Ontario's Mental Health System" (2008) 20:9 *Windsor Rev Legal & Soc* online: *WRLSI* <http://wrlsi.ca/about-us/past-issues/>.

[95] *Re K.S.*, (Ont. Cons. & Capacity Bd.) (6 March, 1991) cited in *R v Webers* (1994), 95 CCC (3d) 334, [1994] OJ No 2767 at para 28 (Ct J (Gen Div)) (QL).

[96] *Supra* note 94, see also and Source 85 *Re Koch* (1997), 33 OR (3d) 485 at para 69, 27 OTC 161 (Ct J Gen Div) [*Re Koch*].

[97] *Ibid*.

[98] *Supra* note 95.

[99] *Supra* note 10.

death, where at times mental illness amounts to just that. And even more importantly, it's vital to assure that people possess autonomous decision making over ones live, and that can only happen if folx are properly resourced. Autonomous decision making must be at the core of mental illness in relation to MAiD, psychiatric care, in times of crisis and throughout chronic treatments.

But I started thinking, if people with mental illness have not possessed an inherent sense of autonomy in their decisions throughout history in the context of institutionalization, crisis, psychiatric care and other sources, where legislation has upheld this very principle, why are individuals who seek to access MAiD with mental illness as their sole underlying condition suddenly able to make autonomous and free decision making when it comes to their death? The core principles of mental health and health law look to prevent suicide and death due to mental illness. In fact, people's rights are stripped away to assure someone is prevented from committing suicide, legislation backs this up, where did the sudden shift come from, where all of a sudden individual have the ability to choose death and legislation assures it? Again, I want to state that I do not possess a specific viewpoint when addressing this topic, I am simply displaying both sides of the same coin, asking some questions to prompt critical thinking for all of you as the audience. So, take a second, pause the podcast, write it down, what is with this sudden shift in the approach to accessing death? Is it under the premise that one is a rational thought to access death through MAiD, while another is an impulsive notion that is derived from mental illness or a flare in one's psychiatric condition? Will there be adequate safeguards present to assure that they are not interchanged when looking to access MAiD? What sort of safeguards can guarantee that? Will provincial legislation that "protects" people with mental illness by institutionalizing them change as a result of MAiD legislation changing to allow people with mental illness to access MAiD? Will individuals no longer be subjected to overbearing psychiatric care because MAiD legislation exists? Take a moment and ponder, think about these questions deeply. They truly matter when discussing the role of autonomy and the goal of the government when enacting MAiD for those whose sole underlying condition is mental illness.

Now that I have outlined what I am referring to when speaking about mental illness and dignity in this section, I think it's important to understand how the two co-relate. Interestingly enough, Denise Reaume has stated that "Dignity is peeking out of various corners of the legal system, sometimes explicitly, if timidly, heralded by the courts, sometimes lying beneath the surface of new developments awaiting discovery."[100] This concept of dignity peeking out from various corners shows us a light at the end of the tunnel, where society, the judiciary and parliament are beginning to shift their mentality to include the principles of autonomy into legislation and court decisions regarding mental illness.

When I was conducting the research for this podcast, I came across an objective of health care that resonated with me. Gordan DuVal mentions that "the primary goal of health care in general is to maximize each patient's well-being. However, merely acting in a patient's best interests without recognizing the individual as the pivotal decisionmaker would fail to respect each person's interest in self-determination -- the capacity to form, revise, and pursue his or her own plans for life. Self-determination has both an instrumental value in achieving subjectively

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[100] Denise G. Réaume, "Indignities: Making a Place for Dignity in Modern Legal Thought" (2002) *Queen's LJ* 28:61 at 63.

defined well-being and an intrinsic value as an element of personal worth and integrity."[101] He states that "autonomy is a cherished value", and I tend to agree with that.[102]

The concept of dignity is vital in health law, mental health law and end-of-life ethics. But, respectfully, the concept of dignity if much more important in the context of personal decision making and adequate resources regarding treatment, medication and psychiatric care for people with mental illness. This is not only in reference to end-of-life ethics, but for those who live with mental illness in everyday life. It starts with simple questions, like: do we truly have dignity in the health care system if there is such a discrepancy in who can access care? Is there dignity in the health care system if only those who have financial independence can access social workers and other for-profit therapy sources? Do we truly have dignity in our health care system if people with mental illness are waiting years to access psychiatrists? Do we truly have dignity in our health care system if people feel as if they have no other choice than the access end-of-life ethics out of societal and financial desperation? Do we truly have dignity in our health care system if people feel as if they do not have a voice or a choice in their treatment, medication and ability to access care?

Why do I say this? Because regardless of how evolved our society may be in relation to the mentality we hold of mental illness, society and government are not responding to the evolved importance of adequately treating mental illness. Many scholars have written about this discrepancy in resources and the lack of meaningful change from both provincial and federal governments. During my interview with Dr. John Maher, he states that "I am one of about 150 of the 5000 psychiatrists in Canada who only work with the people who everybody else says can't get better. And I and my colleagues who do this work are sitting here and saying, 'yeah people can get better', we need the treatment, we need it funded and supported… The economic argument that says "oh, we can't afford this" is absurd – the Mental Health Commission of Canada has been publishing documents for decades showing billions of dollars will be saved if we fund health care properly."[103] Government is not financially contributing to the wellbeing of those in our society that require mental health support, they are not responding to the ingrained intergenerational trauma, poverty and class differences that create situations where mental illness becomes progressively worst. Government is not responding with appropriate and specialized treatment options for those with severe mental illness, those who would be more likely to access MAiD due to the severity of their medical and living conditions. Without these important responses, without the resources, without the money being invested into treatment, research and providing an appropriate living allowance, where is the dignity?

When looking at dignity and mental illness, we must look at every aspect of each principle, that dignity and mental illness hold significant meaning as they interrelate. Both dignity and mental illness have a vast amount of meaning, so when we speak to dignity for instances, we must look to the principles of autonomy and autonomous choice, and when we speak to mental illness we must look to how people with psychiatric conditions were treated throughout history, and how the lack of resources are perpetuating that same treatment in the modern day. Without appropriate resources and government providing access, how is a person expected to make a

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[101] *Supra* note 1.
[102] *Ibid*.
[103] *Supra* note 20.

truly autonomous decision regarding whether they wish to access MAiD to end their lives? How can someone truly weigh their option to die with dignity if they are not given a fair chance at life? In many ways, these are the concepts that we spoke about in our previous section with Heidi Janz, Catherine Frazee, Alex Shadenberg and Josh Lamers' comments. How can someone be free to make a choice if the choice is only there for some and not others?

At this point in our analysis, we are not looking at the concepts of consent or capacity, not yet. Instead, were looking at a person's autonomy. We are looking at whether a person is able to truly make an autonomous decision, and in turn, feel dignity in their decision. If an autonomous decision is not made regarding one's treatment, medication or ability to access resources, does a person truly possess dignity in the context of their mental health?

In *AC v Manitoba (Director of Child and Family Services)*, Justice Abella analyzed a minor's express refusal to consent to a blood transfusion, where if refused, she was expected to die.[104] This case analyzed whether a minor was able to make medical decisions regarding her own life, even though she was seen as vulnerable due to her age. This case was compared to *Carter*, where an individual may be seen to be "vulnerable", even if they themselves do not believe to be vulnerable, but the law does.[105] The conclusion of the analysis looks at the blanket prohibition excluding mature minors from physician-assisted dying regime as a violation of Section 7 of the *Charter*. But in the reasoning specifically regarding s. 7's protection of liberty, something caught my eye. The text wrote: "the right to liberty was violated because the prohibition denied individuals the right to make decisions about their bodily integrity and medical care."[106] This case was in the context of a mature minor but let's set it a little more broadly. Let's look at mental illness in general, not in the context of a minor or mature minor, but within the parameters that exist involving those 18 years-old and above. The text stated that the right to liberty was violated as individuals were unable to make autonomous decisions regarding their bodily integrity and medical care due to a blanket exclusion. Would the failure to provide adequate and appropriate medical care for those with mental illness also result in an inability to make autonomous decisions? Would there be a violation of a persons s. 7 right to liberty if they were unable to access care specific to their medical condition because such care does not exist? Follow with me for a second, if a person is being told they have the right to make any decisions regarding their medical care and bodily integrity, and what they choose to access, such as appropriate psychiatric care from specialized physicians, adequate talk therapy from social workers, specialized trauma treatment, etc. do not exist, isn't that a violation of their ability to make autonomous decisions, and therefore a violation of s. 7 of the *Charter*? How about those who choose a specific type of treatment, but do not have the funds to personally pay for such services they choose to utilize for their own care, isn't that a violation of someone's ability to make autonomous decisions for their bodily integrity and medical care?

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[104] Constance MacIntosh, "Carter, Medical Aid in Dying and Mature Minors" (2016) McGill Journal of Law and Health 10:1 online: *McGill Journal* <https://www.canlii.org/en/commentary/doc/2016CanLIIDocs161?zoupio-debug#!fragment//(hash:(chunk:(anchorText:''),notesQuery:'',scrollChunk:!n,searchQuery:'mental%20health%20',searchSortBy:RELEVANCE,tab:search))>.
[105] *Ibid*.
[106] *Ibid*.

Isn’t the inability to access care the same principle as a blanket exclusion to access MAiD for mature minors as seen in *AC v Manitoba*? Both are as a result of state conduct producing an inability to access care, both are as a result of a failure or inability to act, so why does one violate a person’s sense of liberty and inherent dignity, but the other is seen as an oversight by the government? How does the logic follow? If a choice exists for some to access MAiD, but no choice exists to access appropriate resources, is there even really a choice? Is it truly autonomous decision making?

It could be argued that one is a result of legislation and one has not necessarily been codified. But, I would also counter this argument with the preamble of Bill C-14 and Bill C-7. I read this quote earlier, but Bill C-14’s preamble states: “And whereas the Government of Canada has committed to develop non-legislative measures that would support the improvement of a full range of options for end-of-life care, respect the personal convictions of health care providers and explore other situations — each having unique implications — in which a person may seek access to medical assistance in dying, namely situations giving rise to requests by mature minors, advance requests and requests where mental illness is the sole underlying medical condition;”[107] On the other hand, Bill C-7’s summary and preamble does not reference the non-legislative measures that support the improvement of a full range of options for end-of-life care. It can be argued that Bill C-7 adds onto Bill C-14’s legislative powers, therefore not overriding the preamble regarding developing non-legislative measures. But the non-legislative measures may be the key to avoiding accountability and challenges to government action. It may be the loophole to avoid accountability in equal access to health care and regulating government actions in relation to accessing mental health resources.

The SCC in *Eldrige v British Columbia (Attorney General)* held that any policy or procedure that is governed by a government entity or by an actor of the government may be constitutionally challenged.[108] The *Eldrige* case spoke to the actions of a hospital that are governing the objectives of the government. For our purposes, I quote *Eldridge* to provide some context regarding the possibility of constitutional challenges that could arise as a result of the promises to improve mental health resources – but more so regarding the inability to provide appropriate, equal and accessible mental health resources to all. At the present time, mental health resources are not seen as readily accessible to all. It is well known in Ontario that accessing mental health resources takes at least 1 year but ranges more towards 3-5 years.[109] If a person wishes to access a private therapist, such as a psychologist or social worker for talk therapy, the price can range from $100-$450 a session. For those who are affected by poverty, homelessness, discrimination, disability, etc. it is not feasible to spend $100-$450 a session, where that amount could be the entirety of an individual’s stipend for food per month. The availability of free services is either accessible only to the most severe mental disorders, or hold a multi-year wait-list to access, yet for-profit measures that also advance the objectives of the government are more easily accessible in timing, but cost people money they do not have.

Who governs these programs and initiatives? The government. Provincial governments undertake health care services but are falling sort of actually helping those in need. The ability to

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[107] *Supra* note 64.
[108] *Eldrige v British Columbia (Attorney General)* [1997] 3 SCR 624 at 661.
[109] *Supra* note 20.

challenge the system takes years, but *Eldrige* has made it clear that any non-government body that looks to advance the objectives of a government entity can be challenged. Maybe it's time… but more on this a little later.

My mind kept trying to reason this principle, trying to understand why is came to be that the right to die exists but the right to live a comfortable and dignifies life does not. Then, it hit me, it goes to the significant and overwhelming stigma that exists within the ideology and remedies surrounding mental illness. We see the rhetoric of stigma when its election time – we see politicians enter the race and either applaud or denounce mental health initiatives that came before. We see this rhetoric that people with mental illness are trying to "fraud the system", looking to get "hand out's" or try to "avoid working to get money from the government." But this rhetoric is simply fueling the stigma that exists around mental illness and upholds the stigma. It is this understanding that mental illness is "not that bad", or anyone can "fake" a mental illness to avoid "contributing to society." These statements only further stigmatize mental illness and only further widen the gap between those who need care and those who can provide it.

This stigma exists like a cloud in our health care system, legal system and at Parliament. It affects the way in which law is created, how medical decisions are determined, whether treatment is made and deems what is "effective" for mental illness and what is not.

I would like to draw on two opposing perspectives that make up the perspective of dignity in relation to mental illness. Denise Reaume states that "Respect for human dignity is often assumed to be one of our most cherished social and legal ideals. It hovers over our laws like a guardian angel." On the other hand, mental illness is riddled with stigma that hovers over our society like a cloud. Stigma can appear in various ways – for example, in how mental illness has been referenced throughout history, where individuals were categorized as deviant, weak, or are faking it; historically mental illness was referenced as a condition that requires heavy doses of medication, as something that can be easily cured through medication alone. Archibald Kaiser quoted Michael Perlin's warning that "sanism" permeates the legal system - wherein "decision making in mental disability law cases is inspired by (and reflects) the same kinds of irrational, unconscious, bias-driven stereotypes and prejudices that are exhibited in racist, sexist, homophobic and religiously and ethnically bigoted decision making."[110] Stigma also shows itself in conversations of MAiD, dictating that mental illness is not "bad enough" to warrant the use of MAiD, that mental illness cannot be cured at all – therefore warranting MAiD, that individuals with mental illness are inherently vulnerable, stating that people with severe mental illness do not have any capacity to make their own decisions, and, in a way, dictating that people with mental illness have little self-control. There are multiple viewpoints on mental illness in the modern day, and each perspective has a sense of stigma attached to it one way or another.

Scholar Emily Wilson comments that "It is common for people to draw strong distinctions between mental and physical illnesses. This perspective is often grounded in the assumption that since mental illness is not physically visible, it is an ailment of the mind rather than the body. This has partially led to mental illness having become highly stigmatized, and often believed to

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[110] Archibald Kaiser, "Canadian Mental Health Law: The Slow Process of Redirecting the Ship of State" (2009) 17 *Health L J* at 141.

not be a “real illness”. mental and physical illnesses are closely linked in numerous ways.”[111] Aaron Dhir pointed out the decision of *Fleming v Reid*, which we highlighted a little while ago in this segment - where the court states that “[m]entally ill persons are not to be stigmatized because of the nature of their illness or disability; nor should they be treated as persons of lesser status or dignity. Their right to personal autonomy and self-determination is no less significant, and is entitled to no less protection ...”[112]

I think the comments from *Fleming v Reid* really resonate in this podcast, specifically because it holds multiple connotations for our interpretations. First, it speaks to the concept of dignity in relation to mental illness as a right to personal autonomy, where a mental illness should not lessen one’s sense of dignity or determine whether one possesses dignity in the health care system, judiciary or in the creation of legislation. And second, not only should people with mental illness not be stigmatized for their illness to be refused from accessing MAiD due to controversy regarding the severity of a condition, but mental illness should not be stigmatized by society and government when creating policies and programs regarding access to care. There should not be a distinct split in who can access care based on their financial status leading to a dangerous place where some believe that they are more deserving of care and others think they should access MAiD instead. This is where the danger lies, where an individual may be pushed to access MAiD when it is not their first choice but are not given adequate care and resources from the government, and therefore believe MAiD is their only option.

Professor and scholar Archibald Kaiser commented on the stigmatization of mental illness, stating that “The new prominence of the need to destigmatize mental illness and to combat the harmful effects of prejudice would suggest a logically consistent shift away from laws based on the facilitation of intervention, towards legislation fostering social inclusion.”[113] This understanding of the harmful effects of prejudice has been a central theme throughout this discussion, where the need for “legislation fostering social inclusion” has been the key message by those presenting to Senate during the Bill C-7 debates. What I found interesting, is that in the paper Professor Kaiser wrote, where he produced this comment, was actually from 2009. In 2021, 11 years after this comments was made, we are - arguably – no closer to a piece of legislation that fosters social inclusion for people with mental illness or mental disabilities. In fact, many can claim that it is quite the opposite, that Bill C-7 produced legislation that moved us much further away from facilitating social inclusion and actually accentuated the gap between people who have mental illness across the “social classes.”

So, in the spirit of defining dignity in context to mental illness, I will create a quote that we will share on this podcast. “The bright light of dignity shines down onto earth and the clouds of stigma prevents the light from reaching us.” What a pity. If this podcast doesn’t take off, then I can always become a poet.

In identifying this cloud of stigma, it is that much more important to identify the use of autonomy and self-preservation when dealing with mental illness. Currently, there exists a level

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[111] *Supra* note 27 at 310.

[112] Aaron A. Dhir, “Relationship of Force: Reflection on Law, Psychiatry and Human Rights” (2008) 25:103 *Windsor Rev. Legal & Soc. Issues* at 109 online: *WRLSI* <http://wrlsi.ca/about-us/past-issues/)>.

[113] *Supra* note 110 at 141-143.

of mistrust for the medical and health care systems due to stigmatization. This is especially true for racialized folx, Black, Indigenous and People of Color, LGBTQ+ folx, people with disabilities, etc. Minority groups find it difficult to find doctors they can relate to, or those who understand the circumstances in which someone lives. Many feels as if they do not have a choice in who their psychiatrists are, what sort of diagnosis they are receiving, whether treatment practices are effective or accurate based on cultural standards, as opposed to cis-gendered, heteronormative, white, ableist practices and mentalities that seem to dominate the health system. Many feels as if medical practitioners mitigate their pain and suffering with mental illness, hold an unrealistic expectation of recovery, and often utilize the medical model into their analysis, using countless medications despite the debilitating side effects to no avail.[114] In mentioning this and trying not to go too far out of the scope of the research on mental health and MAiD – it is still vital to understand that currently, people who live with mental illness do not have, or feel that they do not have autonomy in their health decisions regarding treatments, medications, diagnoses, medical practitioners and now MAiD. And this is because of the lack of resources available that disproportionately affect BIPOC people with mental illness, but also that the stigma attached to mental illness still appears to prevail when discussing the need to create adequate resources for people with cognitive and psychiatric conditions.

It is not entirely the fault of players in the health care system that the conversation of suicide and assisted suicide are looked down on. Our health care system is designed to prevent people from committing suicide or thinking of suicide as an option.[115] It is a prevention method geared towards recovery but may not consider that some illness' may not have a likelihood of recovery, including mental illness. Dr. Ryan Tanner writes about this in depth, stating "psychiatrists who treat mental illness are trained to prevent suicide and their clinical experiences informs that posture towards suicidal thinking: embedded in a recovery model as something that is "remedial" and that suicide is a symptom of a condition rather than the end to suffering, also that it can be treated as a preventable symptom rather than rational assessment."[116] And of course, who would I be if I did not present to you an opposing opinion: during my interview with life-long psychiatrist Dr. John Maher, he stated that "when you look at suicide n Canada, about 4000 people will [commit suicide], and about 23% of those who will commit suicide, will try again, but 7% will actually complete suicide… it's a horrific number, as a civic and moral duty that suicide prevention… is a critical thing to do. And yet, were about to offer suicide to people who otherwise wouldn't have completed it, and were about to offer suicide in a context where we have a horrific lack of mental health services, only 1 in 3 adults get mental health services and 1 in 5 children… people wait up to 5 years to receive services."[117]

So, in an area that is so saturated by stigma, does individual autonomy truly exist in decisions relating to one's mental illness? When there lies a fundamental issue in accessing services, is a persons decision truly autonomous?

Is someone truly able to choose how they are treated by the health care system, by parliament or by the judiciary when it comes to making decisions regarding their health and mental illness

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[114] *Ibid*.
[115] *Supra* note 48 at 150.
[116] *Ibid* at 151.
[117] *Supra* note 21.

treatment? Is there autonomy where choice does not really exist? Which brings me back to a conversation I started earlier, can someone truly make a choice about their life if there really isn't a choice to make? When there isn't adequate care available, when wait times are so long it becomes defeating? When someone is forced to drop out of school, or quit their jobs because their mental illness becomes to much to bear, is it truly a choice at that point? Is someone living with autonomy if they are forced to refuse treatment in order to qualify for MAiD to escape from a lack of adequate resources and access to care?

The courts attempted to present a remedy to the lack of autonomy, as seen in the 2003 Supreme Court of Canada (SCC) decision of *Starson v. Swayze*, where the court held:

> Ordinarily at law, the value of autonomy prevails over the value of effective medical treatment. No matter how ill a person, no matter how likely deterioration or death, it is for that person ... to decide whether to accept a proposed medical treatment.[118]

On this point, scholar Shawn H.E. Harmon states, "Autonomy is grounded in respect for the worth of human beings: it encompasses physical, psychological, and legal liberty and the right to be free from controlling influences (of others and of personal limitations) with respect to same."[119] Though, we have seen instances where this decision has not been honored. Specifically, in upholding certain portions of provincial mental health acts that strip autonomy away, through the ability to access MAiD but not adequate health care or mental health resources.

I know this is something that I have repeated multiple times, but it is truly the reason why scholars find the amendments from Bill C-7 to be so problematic. That individuals are unable to make a choice in life but can choose to die out of desperation of their condition. It is seen to be extremely problematic that individuals are being told they have a choice, when no choice actually exists. It is being dulled down to a choice of choosing to access MAiD or not. But the alternative of living in an inaccessible world that fails to create legislation, policy or initiatives that can address systemic issues, stigmas and would aid people's conditions, do not exist.

Scholar Jonas-Sébastien Beaudry authored "The Way Forward for Medical Aid in Dying: Protecting Deliberative Autonomy is not enough" and he created an analogy that was very helpful in understanding the true discrepancy that exists in this claim that individuals are living with a choice when told they are able to access MAiD. He states that this is a "crude scenario" and with that I will provide a trigger warning

TRIGGER WARNING – the next 2 or so minutes will be referring to death, guns, bullets and shootings – please skip past this section, or pause this episode and find another incredible podcast from the CIAJ's website or wherever you find your podcasts.

> Suppose I hold you at gunpoint. I offer you a choice between handing your wallet over or being shot between the eyes. Is your decision autonomous? If you decide to give me your wallet, you might seem coerced, but are you? You can truly choose to die. To

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[118] *Starson v. Swayze* 2003 SCC 32 at para 7.

[119] *Supra* note 19.

> make sure of this, I have secured the help of a medical doctor and a psychiatrist who will ensure that you have sufficient intellectual abilities to understand your situation, and the consequences of your choice if you choose to be shot. I will explain in great detail what the bullet will do to you. If you choose to die, I will have you confirm in writing before two independent witnesses that this is what you really want. Before pulling the trigger, I will ask you one last time if you want to go through with your decision to hold on to your wallet. You are mentally capable of making this fully informed choice and, in that sense, you are acting autonomously. In another sense, however, it seems intuitively odd to think of your choice as autonomous. It appears, on the contrary, that I have encroached upon your freedom of choice and severely restricted your autonomy. I deprived you of a much greater range of options to which you were entitled (such as spending the money in your wallet, say, on music lessons). Most of us would intuitively agree that precautions purporting to ensure that any choice was truly "your" choice did not protect your overall autonomy. Two understandings of autonomy emerge from this crude scenario: one that focuses on the quality of the choice itself, and one that looks at the context within which the choice is made.[120]

Just to be clear that's the end of the triggering section.

This is precisely the issue at hand, people are being fed this understanding that this is the only choice available. In reality, another choice feels unattainable because of the government failure to act on providing mental health resources that are effective and produce meaningful change to a person's circumstances. Meaning, adequate financial aid, a living allowance, accessible talk therapy, accessible specialized cognitive programs for specific mental illnesses, lessened wait-times to access psychiatric care, etc. Therefore, is someone truly able to make a meaningful choice regarding their mental health? Is someone truly able to say they are making an autonomous decision when it feels as if someone else is making that decision, when a person is not given the chance to live, how can they choose to die?

Beaudry continues: "A key justification for its decision was that a carefully designed legal framework could set up safeguards that would protect the autonomy of potentially vulnerable persons receiving MAiD. Those safeguards, I argue, primarily attended to one dimension of autonomy: the micro, deliberative quality of the choice to die. They paid insufficient attention to the macro, contextual factors framing this choice."[121]

And with that, we come to the end of episode 2. In this episode, we explored the changes to MAiD legislation from Bill C-14 to Bill C-7, and we explored how dignity and mental illness interrelate. We spoke of the definition of mental illness and the definition of dignity in relation to mental illness, we looked at the history of mental illness, the use of mental health legislation to protect the vulnerable under the guise of safety, we looked to critiques of current services and the downfalls to the lack of resources, we looked at the impact of stigma in relation to mental illness and we tied them all together by continuously analyzing the impact of autonomy and autonomous decision making within the context of mental illness.

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[120] Jonas-Sébastien Beaudry, "The Way Forward for Medical Aid in Dying : Protecting Deliberative Autonomy is Not Enough" (2018), 85 *SCLR* 2d at 335-385.

[121] *Ibid*.

In the third and final episode, we will explore how mental illness, medical aid in dying and dignity relate, as well as the impact of MAiD legislation on cognitive disorders.

Please feel free to share this episode and the entire series with your communities. Also, if you would like some more information on the concept of dignity, or the framework of MAiD outside of the context of mental illness, please check out episodes 9, 10 and 11 of the "In All Fairness" segment, hosted by the CIAJ, where I explore how the judiciary incorporates dignity into their decision making.

My name is Roxana Jahani Aval, until next time.

Episode 4:

6. How do mental illness, medical aid in dying and dignity relate?

One of my life-long best friends, Deniz Samadi, who is also a recent grad from Queen's Law School, sent me a YouTube video of a short film that depicted a couple checking into a hotel suite for the weekend in Nevada. It was a seemingly normal experience, similar to what couples do when they go on vacation. They laughed, enjoyed themselves, and at about half-way through the short-film, the female character began acting frantic about the time, that time went by too quickly that day - and it was almost "8 pm". Shortly after a man came to the door who identified himself as a dying with dignity nurse, someone who can administer the medication needed for this young woman to utilize medical aid in dying die interventions. The short film never revealed what condition she suffered from, but instead showed the overwhelming emotions this couple goes through. From stating that she wishes to proceed, to die with dignity, from being asked if she was sure of her decision. To actually administering the medication, taking it and waiting for it to take effect. The couple laughed, cried and shared their love in those final moments together. It was an extremely emotional short film to watch, going from two seemingly ordinary people checking into a hotel room, to ending the film with this male character holding his partner in his arms as she passed away.[122]

We read about dying with dignity in the news, in MAiD legislation, in stories that patients' families publish post-mortem, even in intervener factums – we look at dying with dignity through a legal lens, where we can analyze which government said what and how the courts decided cases of such a personal nature. But we never truly see it happen. We aren't in the room when an individual decides they want to die with dignity instead of live a life of suffering, or a life where they grow weak and remember their last moments as painful. I won't speak for everyone involved, as some may have experienced it with a family member or may choose to utilize MAiD at some point in their lives – but we, in the legal community, talk about this concept of dying with dignity from an outside perspective, maybe never truly understanding

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[122] Omeleto, "A young couple gets a hotel room for the weekend – but for very different reasons…" (2020) *Your Day – Omeleto* online: *Youtube* <https://youtu.be/X9MAf245Yag>.

what it means to lay in bed holding your loved one as they choose to end their suffering and die with power over when, how and where they pass. Even watching this short film provided a brief look into the decision, one that takes a lot of rumination and conversations with family to truly choose medical aid in dying for one's life. We dissect this decision and look at the vulnerability of individuals who look to utilize MAiD, we advocate for or against MAiD amendments, we argue amongst ourselves, all to assure that someone has the ability to spend their last day with their loved one, to be held in their loved one's arms while they pass away peacefully.

I mention this because I think we get caught up in the technicalities and the legality of it all, without truly taking the time to step back and realize that human beings, in our community, are utilizing these provisions in a way to uphold their dignity and autonomy. Albeit, not everybody, as I mentioned that some may utilize MAiD to alleviate their socio-economic suffering. I personally just needed a moment to remember exactly why I wanted to create podcasts on this topic. I needed to remember that this topic affects every part of a patient's life and their families lives as well. Jonas-Sébastien Beaudry included a beautiful quote into his paper "Somatic Oppression and Relational Autonomy: Revisiting Medical Aid in Dying through a Feminist Lens", where he quotes Annette Street and David Kissane saying "Acceptance of the decaying body is a constant reflexible process--a project of the self that continues to the end. Such a project requires the dying person to constantly reconstruct and reframe a sense of self, as the body becomes more demanding, unstable, unreliable, and frail."[123]

I realized how much I needed to form a humanistic lens and understanding of a topic that has been dissected from a legal and ethical standpoint for years. I needed to remember how much this issue affects the human body, how it affects people, mind, body and soul. I needed to remember that despite the controversy on the topic, despite the split perspectives, the papers, the analysis, the medicine, despite it all, this is a conversation of human lives at the end of the day. It is a conversation about someone mother, father, child, friend, colleague, it's a conversation about an individual who may have to face this decision at some point in their lives. It's about those who have suffered for so long, about those who live with these conditions that we deem good enough or bad enough to warrant MAiD. This is a topic I have been advocating, writing and researching about for months. It's about remembering the Sue Rodriguez's of the world, the Lee Carter's, and honoring the contributions they made to challenging end-of-life ethics, when they may not have been able to benefit from their contributions by utilizing MAiD themselves.

To quote the then-Justice Cory in *Rodriguez*, "the life of an individual must include dying. Dying is the final act in the drama of life. If, as I believe, dying is an integral part of living, then as a part of life it is entitled to the constitutional protections provided by s. 7… state prohibitions that would force a dreadful, painful death on a rational but incapacitated terminally ill patient are an affront to human dignity."[124]

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[123] Annette F Street & David W Kissane, "Discourses of the Body in Euthanasia: Symptomatic, Dependent, Shameful and Temporal" (2001) 8:3 Nursing Inquiry 162 at 168, see also Jonas-Sébastien Beaudry, "Somatic Oppression and Relational Autonomy: Revisiting Meidcal Aid in Dying through a Feminist Lens" (2020) 53:241 *UBC Law Review* online: *UBC* <http://ubclawreview.ca/issues/>.

[124] *Supra* note 44, see also *supra* note 38 at 630.

Scholar Gordon DuVal wrote a riveting statement in his paper titled: "Assisted Suicide and the Nortion of Autonomy" – "autonomy is a core value of the law and ethics of health care. The power to make decisions for oneself -- to retain control of one's own destiny -- is central to a meaningful sense of self. The ability to make conscious choices based upon reflection -- the capacity to transform oneself in accordance with an active will -- is arguably a uniquely human endeavour."[125]

Before moving to the next portion of this segment, I would like to leave you all with a quote that quite sums up the humanistic nature of dignity into a structure of safeguards, eligibility and the legality of dying; where Harmon states, "it can thus be said that dignity and autonomy have found a legal voice in the end-of-life decision-making framework."[126]

<u>Suicide</u>:
There was also a quote from *Carter* that I mentioned earlier in our roadmap when I referenced the importance of MAiD legislation. Justice Smith with the BCSC stated that "the evidence supported the conclusion that assisted death already occurs in Canada to an unknown extent and moving to a system of regulated assisted death would eliminate such deaths and enhance the likelihood that proper safeguards could be established."[127] This quote is of monumental importance to our topic, to MAiD and to patients with mental illness who ask to die with dignity.

But, before we enter this conversation, I would like to provide a trigger warning for my listeners, the next portion of the podcast will speak to sensitive subject matter, including the act of suicide, self-harm and conversations of death in general. If you are triggered by these topics, please switch off this episode now and check out some of the other podcasts that the CIAJ have available. If you need support, please reach out to Canada Suicide Prevention Service at 1 833-456-4566

Recently I watched a video from "The National" where Federal Justice Minister David Lametti (SP?), Professor Trudo Lemmens, Dr. Madeline Le and Susan Desjardine were answering questions on medical aid in dying legislation. A question arose regarding those with mental illness making rational vs. irrational requests for MAiD when they are eligible, and how practitioners are expected to differentiate between the two. Dr. Madeline Lee responded: "how do we know that a request is a rational request or is it partially driven by irrational motivations …. It has been almost impossible to distinguish, because they both have rational and irrational reasons to die. Several case examples [show] what it's taken is them accepting treatment for the depression and after the depression is cleared, then it's clear to the provider what the basis of the request was. I've had patients who changed their minds after, and patients who didn't change their minds after, that's why we need the research."[128]

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[125] *Supra* note 1.
[126] *Supra* note 19 at 211.
[127] *Supra* note 44 at 787.
[128] Canadian Broadcasting Corporation, 2020. *Medical assistance in dying in Canada | The National Conversation* online [video]: *YouTube* <https://www.youtube.com/watch?v=L_2EDiuzr58>.

At times, individuals choose to end their lives by way of suicide due to a variety of reasons. These can include the suffering that is derived from their specific illness, severity of their condition, their living conditions and other biological and societal reasons. We understand this to be true through various statistics published by government, through the stories of an individual's family and friends - even outside of the context of mental illness. In *Rodriguez*, the courts received affidavit evidence from individuals who wanted to access assisted suicide, as they stated that "the progression of their degenerative illnesses, agony of treatment, fear of gruesome deaths and testimonial from witnesses who had considered committing suicide by "blowing their head off' among other means, but often found it too repugnant."[129] In fact, Adam Maier-Clayton, a young patient advocating for MAiD for mental illness shared his lived experience with this reality and the community was reminded that "if a patient wants to die, they will -- but being forced to commit suicide is the "brutal way."[130]

In a nutshell, that is how mental illness, MAiD and dignity relate. If a blanket prohibition against mental illness as the sole underlying condition exist, individuals may be in a position to commit suicide in a "brutal way" or in a way that is deemed "repugnant".[131] Where a blanket prohibition does not exist, individuals may not being provided adequate safeguards to protect "vulnerable" people with mental illness, like those individuals who may make rational or irrational requests, those who refuse treatment in order to qualify for MAiD, those who meet practitioners who do not specialize in their specific condition to receive effective treatment. Instead, this concept of suicide in a "brutal way" remains a painful reality for people who wish to end their lives due to their psychological suffering but cannot do so with the level of dignity they wish to preserve. As Adam Maier-Clayton mentioned, a person may be forced to commit suicide in a "brutal way", where a person may be mutilating their bodies, and forcing another to find them in that state (causing intense and possible life-time trauma for a loved one or stranger to endure), and are scarcely given the opportunity to die with dignity. This sentiment is the foundation of this podcast, we are speaking to one's ability to die with dignity. We cannot advocate for choice on one hand and prevent choice on the other. We cannot forcefully uphold a blanket prohibition for people with mental illness as their sole underlying condition to access MAiD and then claim that MAiD legislation does not produce discrimination or harm to people with mental illness. Why can't people with mental illness be given adequate safeguards to prevent a "brutal way" to die, and instead die with dignity as other Canadians are able to do?

Though, there are two sides to this specific argument. That a person should not die in a "brutal way" due to their mental illness, but on the other hand, a person should not die at all from their mental illness. Medical professionals who reference the amendments from Bill C-7 and speak to the concept of irremediable medical conditions continuously state that there is no evidence present that states that mental illnesses are irremediable.[132] In fact, some scholars hold the distinct view that mental illness, with the right treatment, can be remedied to some extent.[133]

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[129] *Supra* note 44 at 789.

[130] *Supra* note 63.

[131] *Ibid*, see also *supra* note 44.

[132] *Supra* note 20, see also Sonu Gaind, "MAiD for mental illness is grave discrimination" (2021) online: *Toronto Star* <https://www.thestar.com/opinion/contributors/2021/03/01/maid-for-mental-illness-is-grave-discrimination.html?rf>.

[133] *Ibid*.

And this moves us into our conversation of irremediable and grevious conditions, which is the next portion of our podcast.

Irremediable and Grievous Condition:
In the same "The National" video, one question spoke to a woman looking to utilize MAiD due to a medical condition that was not categorized as irremediable or grievous, resulting in multiple denials of MAiD requests. When speaking to this, conversation arose of the frustrating moment when a person's MAiD requests is denied, especially when they are suffering. Professor Lemmens spoke up and said that there were reported instances where an individual was referred to a specialized practitioner in their supposed condition who assessed the patients MAiD request and realizes that they were misdiagnosed. When properly diagnosed, the individual's condition improved, and they no longer requested MAiD.[134] This got me thinking about this specific issue in respect to mental illness. I started to think about those who saw professionals, were diagnosed and were treated, but have not seen improvement. And it took me back to my conversation with Dr. John Maher where we spoke about his work as a specialized psychiatrist who works with the most serious cases of mental illness.[135] He states "In the work I do, when I have a new patient referred to me, generally speaking, the first 3 years are sorting out symptoms, and a number a years after that is helping people to reconnect with family, giving them a sense of purpose, and a hope in life."[136] This conversation was particularly interesting because of how Dr. Maher categorized his practice of diagnosing, that it took 3 years to sort out symptoms, where I interpreted this as meaning that his team spent quite a bit of time speaking to the patient, observing them, and then diagnosing them based on those interactions. After diagnosis, then his team will spend about 3 years to manage the symptoms the individual may face with treatment and therapy. I started to think about all of those individuals who may have been mis assessed or misdiagnosed. Where individuals were not adequately assessed, not due to any inadequacies of physicians, but rather the limited time and resources physicians have to service a vast number of patients. Where long wait-times, overwhelming staff and the urgent needs of patients force psychiatrists to quickly diagnose an individual and begin treatment. Again, this stems from the lack of resources from the government, where psychiatrists are forced to function within a broken system. I was thinking of those who received treatments that were ineffective to their actual condition in situations where an individual was misdiagnosed, and are now looking to access MAiD, or may choose to commit suicide due to their ongoing suffering.

Scholar Emily Wilson states that "adding to the unpredictability of mental illness is the fact that many chronic mental illness conditions are influenced by the quality of care and social support which the individual receives. However, this is also true of physical illnesses."[137]

Scholar Emily Wilson analyzed the criteria of irremediability and grievousness of a medical condition in order to satisfy eligibility to access MAiD. These eligibility recruitments and safeguards were created by the court in *Carter*, and further codified through Bill C-14 to determine whether an individual is eligible to access MAiD. The criteria is set out in s.

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[134] *Supra* note 128.
[135] *Supra* note 20.
[136] *Supra* note 21.
[137] *Supra* note 27 at 312.

241.2(1)(c)-(e) of the *Criminal Code of Canada*.[138] It's important to keep in mind that Emily Wilson created her analysis on the eligibility requirements for MAiD for mental illness in 2020, prior to the amendments from Bill C-7 that passed in early 2021. These requirements are meant as safeguards within the codification of MAiD to protect patients. These include:

1. Serious and Incurable Illness – where the seriousness and incurability are assessed as two separate requirements.[139]
    a. Within Serious and Incurable Illness, various factors are considered: that the condition has no known cure, and whether treatment is inappropriate at the point of request.
2. Irreversible Decline in Capacity - this factor is broken down into irreversible decline and capacity as separate entitles, where the concept of reasonable foreseeability of a natural death produces overlap with this factor. Specifically, that some chronic illnesses do not have a reasonable foreseeability of a natural death approaching. Though, this factor is still separate from a reasonable foreseeability of a natural death and dictates that irreversible decline must be separate from terminal illness, as chronic illnesses may have irreversible declines as well.[140]
3. Enduring Physical and Psychological Suffering – these dictates intolerable and enduring physical or psychological suffering. It is wildly subjective to the individual, their medical condition, living condition, health status, availability to resources, access to resources, and an individual's tolerance to pain.[141]
4. Foreseeable Death (which was repealed through Bill C-7)– as mentioned the reasonable foreseeability of a natural death criteria does have overlap with the irreversible decline in capacity.[142] It has been clarified that death does not need to arise from terminal illness, not does it need to be associated with a "malfunctioning of the human body."[143]
5. Informed Consent - is the final eligibility criteria that would require an individual to be fully informed of their option. The decision-making capability is vital to the informed consent requirement, where an individual must have all of the information in order to make an informed decision. If an individual does not understand MAiD, the option of ending their life, or any alternatives to MAiD, then the individual does not have informed consent of their choice. Additionally, if an individual does not have adequate capacity to make the decision to access MAiD, then they do not have informed consent.

Many will argue that a mental illness is mostly remediable through appropriate treatment, so long as the patient has received the correct diagnosis, and has been given traditional treatments that are specific to a correct diagnosis, such as medication, therapy, etc. Scholars Scott Kim and Trudo Lemmens note that "the key eligibility criterion of "irremediable" condition is inherently vague and unreliable, even when applied to the types of severe cases usually mentioned by those who advocate for including psychiatric disorders in the legislation for assisted dying."[144]

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[138] *Ibid* at 307.
[139] *Ibid* at 314.
[140] *Ibid* at 321-322.
[141] *Ibid* at 324-325.
[142] *Ibid* at 325.
[143] *Ibid*.
[144] Scott YH Kim & Trudo Lemmens, "Should assisted dying for psychiatric disorders be legalized in Canada?" (October 4, 2016) 188:14 at E337–E339 online: *CMAJ* <10.1503/cmaj.160365>.

As it currently stands, the irremediable standard allows for an individual to access MAiD due to mental illness, so long as they prove that they are treatment-resistant.[145] Satisfying the assertion that a patient's personal mental condition is treatment-resistant "tick's" off the requirement that a person's condition be irremediable or grievous in order to access MAiD, and legally permits a person with mental illness to choose MAiD (after the Sunset Clause period has lapsed). Every person's condition is different, and irremediability must be determined through a case-by-case basis. But the point of mentioning this is that patients are able to claim that their condition is treatment-resistant through the right to refuse treatment – which has been affirmed in decisions like *Starson* - and therefore trigger eligibility to MAiD, even if a practitioner does not necessarily agree that a person's condition is irremediable.[146] It doesn't mean that said practitioner would necessarily approve the request for MAiD, but simply that they cannot force an individual to undergo treatment. In other words, a patient may approach multiple partitioners over the years and provide evidence for treatment-resistance to trigger eligibility, and a practitioner may agree to the irremediability of one's condition.

But, again, this is where things become tricky. Some professionals, including ethicists and physicians, do not guarantee that a person's mental illness is irremediable. That instead, conditions can be remedied to some extent with the proper diagnosis, treatment and consistency in treatment.[147] Dr. Sonu Gaind stated that "Those who advocate expanding access to MAID propose mitigating this reality with "safeguards." This ignores the fact that irremediability is itself the primary safeguard built into the MAID framework, and bypassing it renders all other supposed "safeguards" meaningless."[148] Dr. Gaind, continues "because we cannot predict irremediability, there is 100 per cent certainty that MAID will be provided to some people who could recover — there is no safeguard against that. Suggesting otherwise is akin to a society that declines to use the death penalty over concerns of potentially executing the innocent, but then implements the death penalty anyway with false "safeguards" to reassure the public even as the wrongly convicted are executed."[149] Dr. John Maher stated, "every single person with severe mental illness can experience dramatic improvements in their symptoms."[150] Dr. Maher is of the belief that this sort of improvement requires "patience and persistence."[151] In a series of tweets, Professor Lemmens writes that "Intolerable suffering is also a 'criterion', but that is subjective interpreted" which equals "not a safeguard. [There is] not even a requirement that all treatments have to be tried first."[152] I have to pause and give a shout-out to Dr. Ryan Tanner for directing me to the quotes I just referenced!

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[145] *Supra* note 20.

[146] *Supra* note 19 at 211, see also *ibid*.

[147] *Supra* note 20, see also *supra* note 86.

[148] *Ibid*.

[149] *Ibid*.

[150] John Maher, "Why legalizing medically assisted dying for people with mental illness is misguided", (11 February 2020), online: CBC <https://www.cbc.ca/news/opinion/opinion-assisted-dying-maid-legislation-mental-health-1.5452676>.

[151] *Ibid*.

[152] Trudo Lemmens "(2) yes, intolerable suffering is also a 'criterion', but that is subjectively interpreted=Not a safeguard. Not even a requirement that all treatments have to be tried first. And what if 'only a few people': we care about Human Rights of few. Do you? Does @NDP", (9 December 2020), online: *@TrudoLemmens* <https://twitter.com/TrudoLemmens/status/1336808287292039172>.

In another article, Dr. Gaind stated that the "Council of Canadian Academics found no standards exist for identifying irremediability in mental illnesses, nor evidence this can even be predicted. The Centre for Addiction and Mental Health similarly found the mental health field lacked evidence required "to ascertain whether a particular individual has an irremediable mental illness."[153] In an article written by Dr. Gaind for the Hamilton Spector, he writes that there is "heightening concern, there is also evidence showing overlap between individuals seeking MAID for mental illness and suicidal individuals whom we traditionally try to help with suicide prevention efforts."[154] In an interview given to the Toronto Star, Dr. Gaind explained that "Assessing irremediability in mental illness is no better than a guess, however many make that guess. We should not be throwing darts at a board to decide who lives, and who dies."[155] So, how can Parliament possibly attempt to create safeguards for something that isn't even proven to necessarily exist? That the nature of mental illness dictates that it cannot be deemed irremediable? That "treatment-resistance" may be a social fallout as opposed to a medical one? – a topic which we have looked at in length and will further explore – that the lack of resources, lack of access to health care or specialized treatments, as well as the refusal of treatment that deems someone as having an irremediable condition in order to access MAiD by satisfying requirements is a social fall out rather than a medical one.

I had the pleasure of interviewing Dr. Ryan Tanner, who has written and spoken about matters relating to assisted suicide, ethics and its intersection with the law for over 10 years. After completing his PhD in Philosophy from the University of Calgary, Dr. Tanner received his JD from the University of Toronto, Faculty of Law in 2015, and further called to the bar in 2017. He then went on to attend the University of Ottawa to pursue his LLM.[156] In my interview with Dr. Ryan Tanner, he spoke briefly about the term, "treatment-resistant", which he referred to it as "refractory mental illness."[157] where he states that "I don't know what the threshold for that is supposed to be. This is where I wish maybe some of the psychiatrists and clinicians were a little bit more honest about certain things and informative in respect to what they say about it. Because what is treatment-resistant? Well, they can say, if it resists 3 or 4 treatments, then we can say, as a matter of English, it is treatment-resistant so far. If there were treatments in the past that make us think they ought to work… and it's not working, and if the condition or disorder is getting worst."[158] I want to add something to Dr. Tanner's remarks around the informative nature of psychiatrists and clinician's contribution, and state that the criteria for treatment-resistance should be clearer. I think both patients and medical practitioners would be more at ease if they had some sort of guideline to follow when considering the nature of a patient's resistance to treatment. But is this feasible? Can we possibly establish a guideline to determine treatment-

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[153] *Supra* note 132.

[154] K Sonu Gaind, "Evidence is needed before including mental illness in assisted death legislation" (October 27, 2020) online: *The Spec* <https://www.thespec.com/opinion/contributors/2020/10/22/evidence-is-needed-before-including-mental-illness-in-assisted-death-legislation.html>.

[155] K Sonu Gaind, "We are poised to soon be ending lives of nondying people", *Toronto Star* (24 February 2020), online: <https://www.thestar.com/opinion/contributors/2020/02/24/assisted-suicide-we-are-poised-to-soon-be-ending-lives-of-nondying-people.html>.

[156] "Ryan Tanner Resume" (2015) online: *UToronto Academia* <https://utoronto.academia.edu/RyanTanner/CurriculumVitae>, see also Interview with Dr. Ryan Tanner (June 18th, 2021) [*Tanner*].

[157] *Tanner*, *ibid*

[158] *Ibid*.

resistance when the threshold is so subjective? Doesn't it ultimately depend on the specific circumstances of the individual to determine whether the term 'treatment-resistant' mental illness can be established? Would a guideline be similar to that of the DSM-V, where a patient needs to satisfy x number of criteria before being diagnosed with a condition? If so, where do factors such as geographical location, access to mental health resources, financial status, family dynamic, personal trauma, systemic barriers, addiction, and many other societal factors come into play? How can we possibly quantify something so incredibly subjective? I think Dr. Tanner's point is important, that more clarity is required to determine treatment-resistant mental illness, but do we think that this is possible, or even worst, that Parliament will put a review to establish such a guideline?

But I do want to add, that the comments made by scholars stating that mental illness cannot be irremediable due to the nature of the condition does not mean it is the view of all scholars or medical experts. Instead that one group of people believe that the irremediable nature of mental illness does not exist, while another group does.

To add perspective to the last point about Parliaments willingness to review and establish a guideline, I utilized a quote from scholar Archibald Kaiser, where he states that "the image of the pendulum has often been used to describe the oscillations of mental health law in Canada and further afield. This metaphor is meant to convey the regular movement of public policy between the points of an easy interventionism based on an assumption of treatability and confidence in the beneficence of intrusions and, at the other pole, a vigorous assertion of autonomy, the right to refuse unwanted treatment and the ability to assert one's preferences."[159] Scholars Scott Kim and Trudo Lemmens wrote, "a review of 66 case summaries of euthanasia published by Dutch regional euthanasia review committees found that most patients who received assisted dying for a psychiatric condition were deemed to have met the criterion while refusing recommended treatments; many likely did not receive all indicated treatments."[160] They continued, "the Parliamentary Special Joint Committee on Physician-Assisted Dying's recommendation that "irremediable … does not require the patient to undertake treatments that are not acceptable to the individual" could be particularly consequential for patients with psychiatric conditions."[161] I will not sit here and claim that every refusal to treatment is to trigger the treatment-resistance categorization to draw a conclusion of irremediability, but the fact that this may happen is still massively significant to our discussion. This is precisely the type of vulnerability and safeguarding that was mentioned within the consultations for Bill C-7, and the concept of vulnerability that is so often written about in legal papers.[162] Where Justice Smith from the British Columbia Supreme Court in Carter stated that "it is possible for a state to design a

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[159] *Supra* note 110 at 139-140.

[160] *Supra* note 144.

[161] *Ibid*.

[162] Maneesha Deckha, "A Missed Opportunity: Affirming the Section 15 Equality Argument against Physician-Assisted Death" (2016) 10:S69 *McGill JL & Health* online: *CanLii* <https://canlii.ca/t/6zj> [*Deckha*], see also *supra* note 120, also *MAiD*, *supra* note 47 at S92, also *supra* note 63 at para 19, also *supra* note 55, also *supra* note 74, also Ken Shulman, "*Carter v Canada*: The prudent position of the Federal Government on mental illness" (2016) *All about estates* <https://www.allaboutestates.ca/carter-v-canada-the-prudent-position-of-the-federal-government-on-mental-illness/>, also s*upra* note 86.

system that both permits some individuals to access physician-assisted death and socially protects vulnerable individuals and groups."[163]

It was like a lightbulb went off in my brain, that it all comes back to the same issue – the lack of resources. I know, I know, we've talked about this, but it legitimately comes back to this issue with every argument I make and every piece of work I look into.

Our health care system, and in my case, I mean Ontario – which arguably can be a great example of the flaws, but also recognizes the privilege of health care in Ontario compared to some other provinces – has a massive gap in access to health care and resources. The health care system is understaffed and overworked. Health care teams are often overwhelmed with long-wait lists, back-to-back appointments with little time for adequate assessment, massive wait-times to access testing resources like MRI's, CT scans, etc. Patients may be sent to a general practitioner or specialist who overlooks some symptoms or results due to their overwhelming schedule, patients may miss appointments or have to reschedule due to the lack of sick days or health days available to them, some cannot miss time at work due to their financial situation and very few offices provide after-hour care that can be accessed. Add the stigma involved with mental illness and all of these factors double in time, where individuals are left suffering from their conditions, just to be misdiagnosed and mis-treated for years at a time. On top of this issue, medical students who complete their MD's are left without residencies to attend because of cutbacks to health care, leaving them without work to satisfy their licensing requirements, leaving the system without enough doctors to satisfy the need. And then on top of that issue, the provincial government continuously reallocates or completely defunds certain programs, cuts back on health care staff and leave patients without care. It always comes back to this issue, the lack of resources by the government, lack of access to health care, lack of adequate legislation to bring sick-days and health days to workers, punishing people on disability works initiatives, punishing people on welfare and blaming previous governments or the federal government and everyone else but themselves for the lack of resources available in the province. This is not a "now" government issue but has been a collective for decades.

Why do I mention this? Because BIPOC people with mental illness are the ones struggling the most. The lack of resources distinctly affects BIPOC people with disabilities and it leaves individuals without the ability to live with dignity, let alone die with dignity. On this point, Josh Lamers stated "the whiteness wrapped up in dying with dignity … it puts forward this notion, or shows the reality, that certain people…do get to die with dignity. But for some of us, that's not really an option. And, I don't know if I want to die within this definition of dignity, because again, it's a very troubling definition and conception, where you're talking about, and I am relating this to the legislation, as many people have critiqued, is circumventing creating a better, more liveable world."[164] So I ask again, how can we confidently say that Canadians are being given the option to die with dignity if they are not able to access resources that may prevent the need to utilize MAiD? Why would we applaud a piece of legislation that leaves out those who experience intergenerational poverty, those who deal with systemic racism and discrimination, those who live within this "whiteness wrapped up in dying with dignity", why would we

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[163] *Deckha, supra* note 162.

[164] *Supra* note 10.

applaud a piece of legislation that purposely leaves out a group of people and claims that dying with dignity in the end-goal for the legislation.

Further, why would we applaud government after government who purposely cut resources to health care and physicians, but claim they are looking to further the dignity of those they serve? In many ways, this is the core of every argument regarding MAiD in relation to psychiatric conditions. It feels foolish to have a conversation about MAiD without explicitly pointing this out, and without explicitly criticizing it, as many scholars and disability advocates have. How can we condone actions that collective push us away from equal access to health care, equal access to mental health resources and then applaud a legislation that does not push us towards equality, but instead forces a larger gap between classes? Many have argued that the legislation is social pressure to die, and the more resources that are cut out at the provincial level make this abundantly clear.

So to move back to the conversation about assessments made by individuals who specialize in the condition in which a person is seeking relief for through MAiD, I would like to point out a quote - The Canadian Medical Association was an intervener in *Carter*, stating that "the challenges physicians will face in making these assessments ... especially in the end of life care context where the consequences of decisions are particularly grave and in a public medical system in which resource constraints are a pressing issue."[165] Where some patients may not have regular access to a physician to express their interest in MAiD over a long-period of time, especially in areas or provinces where access to health care is scarce at best, where many individuals wait months to find a family physician. As a result of the inability to regularly access care, competency may be difficult to assess, and therefore the possibility of providing MAiD to a vulnerable individual is a greater risk.[166] The risk being the inability to properly assess authenticity in someone's request to die.[167]

It goes back to Catherine Frazee's quote, "it's cold comfort, I think, to be offered the choice to die when you are not offered the choice to live a dignified life — when you are not offered the basic supports and the basic dignity that we as Canadians we'd consider, I think, minimal for all members of our community,"[168] This is my third mention of this quote by Catherine Frazee because of how it applies to every aspect of this argument. How can a person be expected to make a free decision to die with dignity if they are not given the opportunity to live a dignified life? To be properly diagnosed and treated, to be given appropriate treatment for their condition, to be heard by doctors and not dismissed, to be given access to medication and health care in an appropriate way, to not be shunned from society because of their financial and socio-economic situation. How can a person be given the ability to live with dignity and die with dignity if they have no power or say in their own care? Where is the dignity? Where is the autonomous decision making? Where are the resources available to battle this?

Another point to consider are the possible legal challenges that may arise once the Sunset Clause is raised - Is there a possibility that once the blanket prohibition against mental illness as the sole

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[165] *Supra* note 88 at 168-171.
[166] *Ibid*.
[167] *Ibid*.
[168] *Supra* note 77.

underlying condition following the sunset clause period lapses, that there will be constitutional challenges against the provision? Will it take a court challenge with significant voices from interveners to prompt a change to the provisions? At this point, it's unclear whether the safeguarding provisions that would be included in the legislation regarding mental illness will be adequate enough to protect people with mental illness who have been mis-diagnosed or mis-treated within the health care system. Would this potential court challenge be the catalyst for change, for the courts to obligate parliament to establish heightened safeguards to protect the "vulnerable" when accessing MAiD through mental illness? At this point, only time will tell.

But there is another point to be made here as well, is there a possibility that the mere existence of mental illness as the sole underlying condition as a way to access MAiD going to be challenged under s. 7? And if it does go to the SCC, will the court look to overturn the eligibility of mental illness for MAiD due to previous decisions, such as *Carter*? As we previously pointed out, the concept of *stare decisis* may affect MAiD legislation.[169] But during that conversation we also determined that if the topic holds a different legal issue, the case may be considered and heard again. Is it possible that a constitutional challenge will be made against mental illness as the sole underlying condition, especially in the context of the irremediable and grievous medical condition requirement to access MAiD, and the clear literature that has been pointed out to contradict that mental illness can be irremediable?

In attempting to answer whether a court challenge can be made, I looked into what the community had to say about the *Carter* decision in relation to mental illness. The Centre for Addiction and Mental Health published a paper titled "Policy Advice on Medical Assistance in Dying and Mental Illness" stating "since the court did not explicitly exclude mental illness in its definition of a grievous and irremediable medical condition, some individuals and groups have argued that people with mental illness as their sole underlying condition should be able to access MAiD. Others note that during the trial process the Court commented that international cases related to MAiD for mental illness were not relevant to the current case (para 111) implying that mental illness is not within the scope of the Court's decision, or at least making the Court's intentions on the matter unclear."[170]

The court in *Carter* held that a medical condition be irremediable and grievous in order to access MAiD.[171] This was a safeguard the court implemented to ensure individuals who live without terminal illnesses or those illnesses that have a possible cure do not access MAiD prematurely. When the amendments proposed in Bill C-7 would allow a complete override of the *Carter* safeguard, the foundation of MAiD is being diminished and overlooked. So, where does Parliament draw the line?

As promised, I want to highlight the other side of the argument for MAiD and mental illness. When interveners in *Carter* outlined that people with disabilities who lived with degenerative diseases were taking their own lives, the court was welcoming to those experiences. The court gave weight to those stories. The court provided a platform for these stories. Now, the conversation has shifted over to the impact of psychological and physical suffering on those with

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[169] *Supra* note 44.
[170] *Supra* note 49 at 2.
[171] *Supra* note 41 at para 4.

long term mental illness and this welcoming nature seems to have dissipated. Advocates have come forward to mention their experiences with mental illness and the suffering that follows. Organizations have written papers, done interviews, provided intervener factums to the courts, showed up at Senate meetings for Bill C-7 amendments, and yet their pleas with Parliament have not resulted in adequate change to the provisions surrounding MAiD, meaning the access to resources and health issue. Is this the work of stigma? Is this because individuals still believe that the overwhelming suffering of those with mental illness should not receive meaningful reform in order to access health care?

Not necessarily. Parliament can only do so much when it comes to health care, as health is a provincial undertaking.[172] It is up to the provincial government to reassess the distribution of health services and to re-examine how exactly appropriate change can be made. But this is only if the provincial government agrees to such as assessment. It appears that the ability to alter the standards of health care are available legally, but the willingness to do so is another issue all together. So, we cannot sit and claim that Parliament is entirely responsible. The provincial government is responsible to undertake review with the health system and allocate additional resources to assure that treatment, partitioners and financial resources are available to battle the on-going rise in mental illness. It is also up to the provincial governments, who are responsible for poverty aid and disability benefits to act, allocate more money, etc. Does this mean they are willing? Historically, the tract records of provincial governments do not look promising for appropriate and adequate change to health standards. Without addressing this, issues with MAiD cannot be appropriately addressed, and we will find that many of the fundamental issues that exist in relation to mental illness treatment and diagnosis will ultimately affect how MAiD legislation is exercised and progressed.

With or without MAiD, a person may decide to commit suicide because of the lack of care and access to treatment for mental health concerns. As mentioned before, a person's mental illness may not be considered irremediable, and to remove the provisions that require such an assessment to be made alters the way in which society functions in the current health care system. It almost allows the health care system to remain the same, since individuals are being given another "choice". Where is the dignity in that?

"Dying with dignity is an important concept and relates to autonomy, beneficence, and justice, all important concepts in Canada's healthcare system**."**[173] If dignity is an important concept to Canada's healthcare system, how can the government allow for this trend to continue, to justify the use of MAiD for mental illness when a person is usually not given a chance to be treated accurately, within a timely fashion, with the right medical practitioners. If the government does not address these points to live with dignity and a fair chance at treatment, how can they possibly state that accessing MAiD for mental illness as the sole underlying condition is considered utilizing legislation to achieve a dignified death?

The final part of the segment looks at consent and capacity, but we will not analyze this in much depth, but rather look to the ways that dignity relate to consent and capacity within MAiD.

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[172] *Supra* note 15 at s 92.

[173] *Supra* note 60.

In this episode, we looked at how mental illness, dignity and medical aid in dying interrelate. We pointed out the humanistic nature of MAiD is often reduced to legal discussions over person-oriented analysis, we looked at the act of suicide and how MAiD looks to alleviate a persons struggle to find dignity in their death, we looked at irremediability and greviousness of medical conditions as they relate to MAiD, we discussed how the lack of resources affects a practitioners ability to assess MAiD eligibility, and we analyzed whether court challenges are possible to pursue for mental illness and MAiD.

Please feel free to share this episode and the entire series with your communities. Also, if you would like some more information on the concept of dignity, or the framework of MAiD outside of the context of mental illness, please check out episodes 9, 10 and 11 of the "In All Fairness" segment, hosted by the CIAJ, where I explore how the judiciary incorporates dignity into their decision making.

My name is Roxana Jahani Aval, until next time.

<u>Episode 5:</u>

The fifth and final episode will briefly conclude the third part of our roadmap by exploring the concepts of consent and capacity, whilst also moving into the fourth and final step in our roadmap by analyzing how cognitive disorders are affected by MAiD legislation. In this episode we are going to briefly look at the concepts of consent and capacity in order to determine that aspect of cognitive disorders and those who live with them.

Moving into consent:

<u>Consent</u>:

Scholar Shawn H.E. Harmon speaks to the "consent model" when discussing medico-legal decision-making, stating that "Medical law now uniformly imposes on clinicians the "consent model," which demands that patients be empowered to make, or participate in, treatment decisions. Under this model, individuals must consent before any treatment (any physical touching) can occur."[174] The consent model positions dignity at the core of its principles.

For the purposes of this work, I must specify that consent is spoken about in multiple ways. First, through the understanding of consenting to treatment, which looks to the "sufficient conditions" that are deemed necessary to establish informed consent, which includes i) understanding what a patient is being asked to consent to, ii) that a mental condition does not prevent a patient to make a decisive choice, iii) that a condition should not prevent a patient from communicating their

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[174] *Supra* note 19 at 210-211.

choice or iv) a condition should not prevent the ability to accept medical intervention.[175] Second, I will speak about the concept of consent specifically in relation to requesting MAiD, fulfilling the requirements to access MAiD and to make the choice to die with dignity.

Throughout my research I found it very interesting that patients are often able to consent to treatment, but it is looked down on to refuse treatment. It was also interesting to see that consent seems to work one way, to consent to the concept of "progression" "treatment" and "helping themselves", while the thought of consenting to end-of-life interventions in relation to mental illness is seen as "giving up", "as not pushing to be better". End-of-life intervention is not being viewed as helping ones' self by relieving themselves from their suffering. So, what gives?

Can we attribute this judgement of the willingness to consent to treatment as positive, but the willingness to consent to MAiD as a negative as a product of ableism? Can we dictate this as stigma of mental illness? When I say this, I don't mean in the eyes of Parliament or the judiciary, but in the eyes of the health care system and society. Do we automatically dictate that treatment is guaranteed healing and MAiD is giving up? It is too naïve and too simplistic, but it appears to be occurring far too often. But this is partly due to the stigma that exists when comparing mental and physical illnesses, that mental illness is seen as a "weak mind", when in reality it's a distinct chemical imbalance, its poverty, it's the lack of adequate living conditions, its facing racial injustice, it's inequality, its childhood or adult trauma, its intergenerational or historic trauma, its addiction. This comparison that states that mental illness is a weak mind is actually multiple inequalities in our system that come back and affect the individual. So, are we functioning under the guise of stigma? Are we looking down on the concept of ending ones life due to mental illness with that stigma in mind at every turn? Unfortunately, our system is still largely based on the medical model, on technicalities of treatment procedures and lacks adequate resources to help patients. That its about the condition itself, and that its less about a persons ability to gain treatment, or to be treated. That its less about the societal factors that would allow for a person to gain treatment, but instead its about a persons ability to "get better", but rather we analyze the medical technicalities of ones ability to receive medication, treatment.

Why does this matter? Because we are looking at ones ability to consent, but also what someone is actually consenting to. Are they consenting to something that they want to consent to, or are being forced to consent? Are advanced directives being given to waive the final consent requirement set out in MAiD safeguards, when a person is not able to consent to appropriate treatments when they still have capacity to do so?

Even when a doctor dictates that a mental illness is not responding to treatment, that individuals are left suffering without adequate relief, the option to die with dignity. This is stigma, this is ableism – this is existing without an option, without a choice, without meaningful autonomy. Some argue that refusing MAiD to individuals where mental illness is their sole underlying condition is valid and a blanket prohibition should be upheld, that mental illness is temporary suffering with adequate treatment available to address it. Others say this mentality itself is

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[175] C W Van Staden & C Krüger, "Incapacity to give informed consent owing to mental disorder" (2003) 29 *J Med Ethics* at 41-43 online (PDF): *NCBI* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1733664/pdf/v029p00041.pdf>.

ableism, the assumption that mental illness is temporary suffering when it can be chronic and debilitating, that it affects more than just the mind, that it takes the wind out of someone to repeat their story to another doctor, to take another medication with more side effects. With this mentality, the stigma of mental illness will continue, the concept of healing and treatment will be upheld to an unrealistic standard, and individuals will feel defeated. When this unrealistic standard is constantly reinforced, and individual may feel as if they are, in fact, treatment resistant and may work their way to access MAiD prematurely – a concept that the court in Carter stated was a fear, that individuals should not be vulnerable when accessing MAiD And should not die pre-maturely when accessing MAiD. These are the fears around consent. So I must ask, how much of the legislation that was created around mental illness was made with the lens of stigma and ableism? I wish I could hear what others have to say, but in that I want you all to think of this. When an individual is being told they are able to access MAiD To end their lives when mental illness is their sole underlying condition, is this an autonomous choice? Or are they doing so with stigma and ableism? This pressure may not be from Parliament or the judiciary, but from society and the health care system? How impactful is societies stigma of mental illness in a person's decision to die with dignity? And, how does consent play a role in that decision?

Capacity: "mental illness can threaten an individual's capacity to make decisions that genuinely reflect their interests. Suicidal ideation, for example, is a common symptom of depression, and even if we accept that not all suicides are irrational or pathological (that is, we reject the "no rational suicides" thesis), the presence or suspicion of mental illness throws into question our ability to access a patient's genuine preferences."[176] This statement by Ryan Tanner encompasses the basis of the capacity argument regarding mental illness and MAiD. Since people's conditions form symptoms of suicidal ideations, actions and thoughts, while some medications that are made to treat such mental illness create the same or similar symptoms, some believe that an individual with mental illness may not always possess the capacity to rationally choose MAiD. Instead, that vulnerability would direct one's decision to access MAiD, moments of hardship, times where a person's mental illness flares and they turn to suicide out of desperation.

Henry David Thoreau in *Civil Disobedience* states: "The *Charter* rights of persons living with mental illness and addiction, and in particular their right to equality, must be respected. These affected Canadians are full members of our society. Questions concerning their mental capacity cannot be used as a pretext for watering down or stripping away any of their civil liberties or human rights."[177] Though, this appears to be happening at a higher rate for people with cognitive disabilities. Patients who live with a degenerative condition are often told they lack capacity to make meaningful decisions or to produce informed consent to access MAiD. This is when their protections as vulnerable individuals must be triggered to guide a partitioners next move in relation to MAiD. This also triggers the need for adequate safeguards to be implemented that do not further strip a person's rights away or shift them to the power of others but upholds the autonomous decision that has been made and affirmed multiple times before capacity has been "lost". This is the moment where practitioner's do not proceed with the MAiD procedure if the

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[176] *Supra* note 88 at 155.

[177] Hon. Michael J.L. Kirby & Hon. Wilbert Joseph Keon (2006): Out of the Shadows at Last: Transforming Mental Health, Mental Illness, and Addiction Services in Canada, online: Senate of Canada <http://www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/repe/rep02may06-e.htm>.

patient no longer consents, and it's clear they no longer consent when they are thrashing around or flat out refusing to participate in the procedure. This is the moment when safeguards are vital to the well-being and protection of the patient, and without knowing what those safeguards are, we are already stripping those rights away. Without being involved in the decisions and consultations to create those safeguards, then someone's rights are being watered down. This may be occurring for people with cognitive conditions, where they no longer have capacity to make an informed choice. But also for those who use advanced directives to assure that they would be able to access MAiD when the time came. These voices are vital in the decision making process when making safeguards for people with cognitive disabilities.

Dr. Ryan Tanner stated that "after all, if mental illness is a threat to a patient's decisional capacity, it remains a threat whether or not it is paired with some other illness or condition. The point is this: if we can demonstrate that otherwise healthy individuals suffering from refractory mental illness should sometimes be eligible for assisted dying, we will also have shown that patients suffering from both physical and mental illness simultaneously should sometimes be eligible as well. The more general question of whether and to what extent any individual with mental illness should be able to access MAID can be answered without reference to the role that physical illness might play in the decision. Thus, it is only necessary to focus on "sole underlying condition" cases. Refractory depression is used as the main example."[178] Dr. Tanner has a point here, which we discussed earlier regarding the compounding conditions, where individuals have mental illness and other physical conditions. The same standard to capacity should be analyzed when a patient is looking to access MAiD when they live with compounding conditions. This standard is not one that lies with mental illness as a sole underlying condition. To categorize that those with mental illness as a sole underlying condition when accessing MAiD are the only ones who should have increased scrutiny on their capacity is short-sighted. Parliament should be cognizant of the stigma that is implicitly peeking through legislation that questions those with solely psychiatric conditions but leaves those with compounding conditions free of increased analysis to their psyche. Again, where is the balance here? Where is this sense of equality between types of disability that the *Truchon* decision was attempting to balance out when removing the reasonable foreseeability of a natural death requirement? Does this feel like we're moving backwards in time?

Before moving onto a discussion on cognitive disabilities, I would like to end this segment with a quote that was incredibly moving and apropos to our conversation here: Professor Paul Miller wrote, "when people with disabilities make a 'choice' to seek their right to die, they do so from the position of a society that fears, discriminates against, and stigmatizes disability as undignified ... is there really a choice at all?"[179]

7. **What about cognitive disabilities – where capacity begins to play a role – and consent?**

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[178] *Supra* note 88 at 155.

[179] Paul Miller, "The Impact of Assisted Suicide on Persons with Disabilities--Is It A Right Without Freedom?" (1993) 9:1 *Issues in L & Medicine* 47 at 54.

When speaking to mental illness as a sole underlying condition in accessing MAiD, we often categorize mental illness with the more traditional definitions and criteria's, specifically those listed in the Diagnostic and Statistical Manual, version 5. But a conversation needs to be had regarding cognitive disorders. Degenerative cognitive disorders are not necessarily considered mental illnesses.[180] Instead, cognitive disorders like dementia affect an individual's cognitive responses, ability to concentrate, remember events, people, or details.[181] Dementia and other cognitive conditions could result in increased feelings of fear, anger, sadness and other feelings that lead to depression, anxiety, panic disorders, etc.[182] Those caring for people with Alzheimer's may feel anger, guilt, frustration, discouragement, worry, grief and social isolation – family and friends may be in a position where they hold a significant responsibility over their loved one with Alzheimer's, including responsibility for their financial, legal and health decisions.[183]

The Alzheimer's Association has outlined a number of conditions that may be included in the categorization of degenerative cognitive conditions to access Compensation Allowances for instance.[184] These conditions include early-onset Alzheimer's disease, adult-onset Huntington disease, Creutzfeldt-Jakob disease, Frontotemporal dementia (also known as Pick's Disease), Lewy Body dementia, mixed dementia, Primary Progressive Aphasia, Progressive Supranuclear Palsy and the ALS Parkinsonism dementia complex and many more.[185]

Therefore, when we speak to MAiD in the context of mental illness, we are not necessarily speaking to cognitive issues. Degenerative cognitive issues may have a differing set of barriers and struggles that require safeguarding to protect vulnerable populations than the safeguards that may exist for mental illness for instance. Cognitive disorders usually progress to a point where an individual does not remember decisions that they made, or feelings that they felt. They may have opted into an advanced directive to utilize MAiD when they had capacity, clarity and lucidity to do so. Once their condition degenerates, and the memory of such a request is forgotten, an individual may end up feeling confused or unsure of their choice, which may result in a resistance to participate in MAiD any longer. This issue does not always seem to affect people with mental illness who seek to access MAiD. Where a decrease in memory or capacity may occur with mental illness, but this is usually temporary, and partitioners will likely wait until the individual possesses control over their thoughts to request MAiD with clarity before being able to administer MAiD to them, in order to satisfy the informed consent safeguard that exists.

Though, there are many similarities between people with mental illness such as depression, anxiety, PTSD, etc. and cognitive disorders like Alzheimer's, dementia, etc. The United Nations Committee for the Rights of Persons with Disabilities' (CRPD) formal commentary from Article

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[180] Alzheimer's Australia, "Information about dementia for young people" (2005) *An Australian Government Initiative* at 1 online: *Dementia.org.au* <https://www.dementia.org.au/sites/default/files/20050700_Nat_HS_6.1InfoYoungPeople.pdf>.
[181] *Ibid*.
[182] *Ibid*.
[183] UT Health, "Alzheimer's Disease" (2021) *UTHealth Harris County Psychiatric Center* online: *hcpc.uth.edu* <https://hcpc.uth.edu/pages/wimi/alz.htm>.
[184] Alzheimer's Association, "Social Security Disability" (2021) *What is the Compassionate Allowances initiative?* online: *ALZ.org* <https://www.alz.org/help-support/caregiving/financial-legal-planning/social-security-disability>.
[185] *Ibid*.

12, paragraph 2 states that those with "cognitive or psychosocial disabilities are at particular risk of having their equality rights violated through laws that remove their legal capacity due to their disability, insisting that states take action to ensure that rights are not automatically divested for those with non-physical disabilities."[186] The report further states: "persons with cognitive or psychological disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity."[187] These are facts that we have identified throughout this podcast, that people with cognitive and psychological conditions are often questioned on their capacity and ability to consent to procedures and interventions such as MAiD. The threshold for determining capacity is seemingly similar for people with physical or episodic disabilities and people with cognitive or psychological disabilities. But the difference remains in the ability to medically determine whether a condition is deteriorating. For physical illnesses, diagnostic tests can be administered to visually confirm the existence or progression of a condition. For cognitive and psychological conditions, diagnostic tests exist for the same visual determination, but diagnostic testing for the existence and progression of a condition more often lies in questioning and answering, written tests to determine whether a condition has progressed, and much more subjective parameters. It is usually up to the medical professional to determine whether a condition has progressed, and if you visit another professional who specializes in the same or similar area of medicine, you may find that the prognosis or progression analysis is different. In this way, cognitive and psychological conditions are similar when determining the capacity or eligibility of MAiD. Personally, I could think of a few points to say about the stigma attached to cognitive and psychological conditions versus the stigma that exists for physical disabilities, but I would like to instead move to the legal challenges that people with cognitive conditions face when seeking to access MAiD.

In my interview with Dr. Ryan Tanner, he stated that "In Canada you can sign an advanced directive … but what I worry about is you have someone who does not understand what is going on anymore… Probably what happens is they wait for the moment that the person is lucid enough and wants to cooperate and maybe isn't aware of exactly what's going on but is not seriously opposed… You can make the case that you are making a decision for this new person that didn't exist before and they never signed off on it, it they really are a new person, and their psychology is so different… it's a live issue. I could be persuaded that it would be permissible if I knew what the protocols and so on were in regard to people who may not want to cooperate with what's going on."[188] When we had this conversation, I informed him that, like him, I am hesitant about how this affects patients with cognitive decline. Especially when it comes to this new conversation on the topic of power-of-attorney's and others making this massive decision for someone.

And on that point, I recently watched a video from "The National" where Federal Justice Minister David Lametti (SP?), Professor Trudo Lemmens, Dr. Madeline Le and Susan Desjardins were answering questions on medical aid in dying legislation. The first question came from a daughter who functioned as a power-of-attorney for her mother, who was at the end-stages of life. She asked when the provisions would be available for a power-of-attorney to utilize MAiD for the person they care for. Justice Minister Lametti stated that it would be within

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[186] *Deckha*, *supra* note 155.
[187] *Ibid*.
[188] *Tanner*, *supra* note 156.

the review on MAiD and would specifically look at how those who seek MAiD with cognitive mental decline like dementia may access MAiD through their power-of-attorney. He stated that "at this time, the law focuses on an individual's consent… we are still not at the stage where power-of-attorney may be used."[189] The moderator then points out that a power-of-attorney has the ability to remove life-sustaining measures such as food, water and oxygen, but is not able to access MAiD for the patient – where one produces suffering and the other may relieve such suffering – where is the logic? Why does the law allow for one measure but not the other? Minister Lametti responds that there have been legal and religious doctrines that distinguish between withdrawing life-sustaining measures and one that is actively working to ending one's life – and this is where the distinction lies – that this loophole is distinctly differing due to the law and traditional understandings of actively participating in allowing death. Minister Lametti states that "these are ethically charged topics".[190]

Another question speaks to the cognitive decline as being categorized as a mental illness to satisfying the requirement that it be the sole underlying condition to access MAiD. The moderator asked Professor Lemmens to comment, where he states that MAiD for those with cognitive decline is a little trickier, where the Netherlands is the only country that allows for MAiD to be used for cognitive conditions at the moment. He identified that there comes a time where the patient is sat down and is being told that they are going to administer MAiD and put them through the process of dying with dignity, and the individual is confused about what is happening.[191] This does produce a dilemma for practitioners, families and the patient themselves who do not understand why this is happening, especially in a state of confusion. So I ask, what are the ethical lines that we draw in the sand? When a patient, who has previously asked for MAiD when they had capacity to consent, no longer remembers such a request, or cannot understand the conversation that occurs before MAiD is administered, when do we refrain from moving forward? Even in the context of the previous point made regarding power-of-attorney's, when another individual is choosing to consent on the patient's behalf, and they are confused, conflicted and concerned, when do we refrain from moving forward?

Minister Lametti mentioned that many medical experts asked for this provision of the legislation to be paused, but that they are continuing to analyze the issue during the summer review, as they are with mental illness as the sole underlying condition all together. But is this wise? Is this a can of worms that parliament is ready to open? What sort of safeguards can be provided by way of legislation to protect individuals who no longer wish to access MAiD in the moment, when they are confused or forgetful of their directive? When accessing MAiD for any condition, including mental illness, individuals have the ability to change their minds. Patients who once requested MAiD, waited the 90 days and were given clearance to die with dignity may change their minds at the last minute. What sort of safeguards can be created when the individual who is accessing MAiD is confused or does not remember making the directive, and now wish to back out, will the practitioner continue anyways? The law has allowed for a waiver of the final consent requirement, but in knowing this, will practitioners continue? I doubt it, based on the ethical and legal implications of continuing to administer MAiD without the individual's clear consent. Does it fall onto the power-of-attorney when the patient is clearly stating they do not wish to die in that

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[189] *Supra* note 128.

[190] *Ibid*.

[191] *Ibid*.

way? Or does the document that states someone wishes to access MAiD, that was signed when they possessed capacity to consent override all other directives, even that of the patients?

A resource listed on Alzhimers.ca mentions a situation that I presume would arise often when dealing with cognitive conditions and MAiD. The question listed states "Can a person in the early stage of dementia request access to MAiD for when they reach a later stage of the disease?" – where the resources states that an individual is able to request access so long as certain conditions are satisfied. These include that the person's natural death is reasonably foreseeable, that the person has been deemed eligible for MAiD after being assessed by a qualified healthcare provider, and that the person has set a date for when MAiD would be administered.[192] The resource also mentions a "waiver of final consent" that patients are able to fill in situations where they would no longer be able to give express consent.[193] It indicates that a firm date must be listed when filling out the form, but that they should indicate a date earlier than what they would want due to the fear of losing capacity before we reach that date.[194] Lastly, the resource indicates that individuals may be able to change the date if they are still deemed capable of providing express consent.[195] The page mentions the amendments made in Bill C-7, and provides that this can be accessed after Sunset Clause of 2-years has elapsed, but individuals do not have to prove that their death is reasonably foreseeable.

The reason I mention this resource is the next portion of the page, where it states that "the agreement to waive final consent will be invalid if the person, after having lost decision-making capacity, demonstrates refusal or resistance to the administration of MAiD by words, sounds or gestures" then MAiD can be refused by the patient.[196] This speaks to Professor Lemmens hesitation when referencing the Netherlands protocol on "The National" video, but also shows that some safeguards that are being implemented can protect the dignity of the patient, even when ones capacity is questioned. I think this eases my mind on a personal level, where I hesitated with the idea that a patient may consent to the procedure and may withdraw their consent once capacity is lost, but medical professionals may be bound to adhere to the directive and administer MAiD to a reluctant individual. This made me question the incorporation of dignity. That an individual may no longer consent, therefore asserting their autonomous decision making, and be ignored because they are told they have no capacity to deny the previously signed directive.

I will mention though, I think this concept has two sides to look at: one side stipulates that an individual's dignity is upheld if they are able to make decisions about their wellbeing when they have capacity, and those autonomous decisions when capacity to consent is present must be honoured. On the other side, that an individual should be able to utilize all of the safeguards available to people when making a decision to die with dignity, such as withdraw their request for MAiD at the last minute, therefore exercising a withdrawal of interventions at the time of

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[192] AlzheimerSociety, "Medical assistance in dying" (2021) online: *alzheimers.ca* <https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/end-life-care/medical-assistance-dying>.
[193] *Ibid*.
[194] *Ibid*.
[195] *Ibid*.
[196] *Ibid*.

final request but are unable to because they are deemed to lack capacity for the reasons of cognitive decline.

By mentioning this, I think we realize that this issue is very complex. That there are a multitude of grey area present when speaking about capacity and cognitive conditions when referring to dignity and the decision to end one's life. With this understanding, how are we expecting Parliament to create comprehensive safeguards to protect the vulnerable in only two years' time in the middle of a pandemic? How can we possibly expect that enough consultations are conducted, enough conversations are had, enough literature is reviewed, and strong safeguards are made if we have such fundamental questions about how a person will unequivocally consent to ending their life when they experience cognitive decline? And how can we expect medical practitioners not to question a person's decision when they are responding to the conversation in a very negative and emotional way?

This is not to say that a person's dignity is trumped by fear of the lack of safeguards, or that people with cognitive conditions should be denied the ability to access MAiD – but that we must take a moment of pause and realize that more time may need to be dedicated to the establishment of safeguards, resources and comprehensive legislation that would assure that a vulnerable patient is protected. This is not to undermine autonomous decision making, or the concept of dignity in end-of-life interventions, but to enhance these foundations of our legal system and a patient's decision to die.

These are really important questions to consider when looking at MAiD in the context of cognitive conditions and cognitive decline. How can parliament be sure that they are administering MAiD to those who wish to access it when they cannot actively share that desire in the moment, and in fact state the opposite intention. We need more literature, more information, more research, more consultations and ultimately, we need more time.

Conclusion:

So, were at the end. We discussed a variety of topics throughout this podcast, and I wanted to leave you with a few thoughts to end off with.

First, I want to highlight again my short-answer that I provided at the beginning of each podcast. Our research topic was "whether individuals with mental illness as their sole underlying condition should be able to access Medical Aid in Dying interventions?" I stated that my short answer is, I don't know. I will also state that my long answer is still I don't know. This was partially to allow you all to decide what you think, but also to state that this issue is much more complicated than yes or no.

One of the topics we looked at was the reality that some individuals may look to access MAiD due to their psychological suffering but are not given clear parameters of what that access to end-of-life interventions looks like. But where is the dignity in that? An individual is being told that they cannot access end-of-life interventions and that other individuals can because of the type of illness they live with. But now, with the amendments from Bill C-7, all other individuals with disabilities can access MAiD so long as they wait the 90-day period from the time of their first request for MAiD. People with cognitive and psychological conditions are told they can access MAiD interventions, but the parameters around the safeguards are not explicitly outlined at the moment. Will they be sufficient? Maybe, maybe not.

The safeguards that were originally created in the *Carter* decision were explicitly clear, that MAiD be utilized for people who have conditions to Ms. Carter and Ms. Taylor.[197] That a person has an irremediable and grievous medical condition, that they are able to give informed consent regarding their request for MAiD. If legislation was made to alter these original safeguards that the court created to protect the vulnerable, are we undermining the original intentions of MAiD in Canada, or are we allowing for the evolution of MAiD to provide more inclusion to people with disabilities whose conditions are not deemed "terminal"?

Are there safeguards that can be implemented to assure that medical professionals are assessing patients in the least subjective way as possible? Do we require that patients be assessed only by specialists in their condition to ensure that patients are not participating in the pre-mature death of an individual? Is there any way to ensure that people who are disproportionately affected by poverty, homelessness, colonization, discrimination, racism, ableism and other socio-economic factors are not requesting MAiD due to their social rather than their medical suffering? Is there any way to safeguard the protection of vulnerable individuals with cognitive deterioration from having their power-of-attorney's engage in abuse or errors in their care when advocating for MAiD? Is there any way to ensure that that people who seek MAiD due to mental illness as their sole underlying condition do not satisfy the requirements of MAiD without the proper diagnosis, appropriate treatments, medications, and resources to promote recovery? How can we ensure that medical practitioners are properly trained to discuss and administer MAiD? Or even ensure that medical practitioners are trained in the proper diagnostic measures when they do not specialize in the individuals specific condition? How do we do all of these without undermining a person's dignity, their right to autonomous decision making? How can we ensure that people are protected but not discriminated against? Where is the balance?

Parliament should treat cognitive and psychological patients with the respect they deserve. To do this, Parliament must be realistic about how impactful MAiD legislation can be without providing adequate resources to remedy the social and financial struggles patients face, especially BIPOC people with disabilities. Systemic discrimination and systemic oppression are alive in Canada, and Parliament cannot silo MAiD into a 'person with a disability' issue alone. Parliament must consider the impact discrimination and oppression have on people with disabilities who are intersectional and experiences colonization, anti-Black racism, poverty, are subject to the housing crisis, unemployment, are immigrants or refugees, and are people of the LGBTQ+ community when attempting to access MAiD and resources for cognitive and psychological conditions.

After all of this I feel as if I am left with questions, and there may never be answers to all of these questions. It feels sometimes that these decisions are not in our hands that we cannot decide to advocate or even predict how the law will be created and practiced. But in reality, it is in our hands in more ways than we know. Disability rights groups work tirelessly to ensure that our voices are heard that there is representation for people with disabilities at each table, that we

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[197] *Supra* note 63, see also *supra* note 74.

are represented in parliament, in consultations, at Senate hearings, during question-and-answer periods, within court cases and at every level of the decision-making process. Frankly, we have succeeded at making our voices heard, one way or another, whether we advocate for or against these amendments. Does that mean the work is done? No, absolutely not. In advocacy, the work is never done, we just move on to the next topic that requires change, and we continue to rally. That is what change requires, that people who are affected by the issue have a say in how that issue is dealt with.

Will we see a constitutional challenge to alter the current statutory provisions that govern MAiD for those with mental illness? Maybe. Will we see a challenge to the amendments where the lack of resources and access to health care disproportionately affect some people with disabilities over others, therefore removing safeguards meant to protect the vulnerable? Maybe. Once the proposed safeguards for cognitive and psychological conditions in accessing MAiD are released, will we see challenges to the lack of adequate protection granted to vulnerable folx? Maybe. All we know is that the concept of dignity, autonomy, freedom of choice, available of resources, access to health care and the ability to access MAiD are in a stage of constant evolution, and it is up to us to inform society that no matter where they stand in this conversation, they have a right to choose.

Now that we have officially reached the end, I hope that I have been able to teach you something about the current state of affairs for people with disabilities in Canada. I want to thank Dean Reem Bahdi at Windsor Law for her guidance during this process, for answering my constant emails at all hours of the day, for meeting with me at a moment's notice, and for encouraging creativity within the stuffy old-school discipline we call law. I would also like to thank Josh Lamers for his time and contribution to this discussion, please check out his on-going with the Collective of Child Welfare Survivors. I would like to thank Dr. John Maher for his time and expertise, please check out the Journal of Ethics in Mental Health for more perspectives on this matter. I would like to thank Dr. Ryan Tanner for his time and contribution to this discussion, in particular the great conversations we had about irremediability and dignity.

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My name is Roxana Jahani Aval, and I hope you enjoyed the series. Please feel free to share the series with your communities! Also, please feel free to contact me for more information or with feedback on the discussion. And to include a memorable quote, "When it comes to human dignity, we cannot make compromises" – Angela Merkel

Thank you for listening to my podcast, until next time.

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