MAiD in Canada: Appendix 1
Treatment Induced Enduring Sexual Dysfunctions

Canada put Medical Assistance in Dying (MAiD) legislation in place in June 2016. This allowed for medical assistance in dying in cases where death was reasonably foreseeable. In 2019, in Truchon v Attorney General of Canada, the Superior Court of Québec declared the "reasonable foreseeability" criterion unconstitutional. This decision forced a review of the original legislation.

The original legislation required an individual to have a "grievous and irremediable medical condition," meaning that a person:

- has a serious and incurable illness, disease or disability,
- is in an advanced state of decline in capabilities that cannot be reversed,
- experiences unbearable physical or physiological suffering from an illness, disease, disability or state of decline that cannot be relieved under conditions that the person considers acceptable,
- is at a point where their natural death has become reasonably foreseeable, taking into account all medical circumstances, and not requiring a specific prognosis as to how long they have left to live.

The review proposed to:

> "retain all existing eligibility criteria but would remove the requirement for "reasonable foreseeability of natural death". It would also expressly exclude persons suffering solely from mental illness".

An amendment eliminating the exclusion of people with mental illness was proposed by Senator Stan Kutcher, arguing that mental illness is as real as physical illness, that it can lead to great distress and routinely leads to people attempting to take their own life.

The arguments against this amendment express concerns that people with mental disorders may be pressured to opt for death, essentially for the convenience of others and of services that are not adequately funded.

MAiD and Post SSRI Sexual Dysfunction (PSSD)

On February 10th 2021, the Therapeutics Initiative in Vancouver hosted David Healy from McMaster University in a webinar entitled Sex and Evidence Based Medicine.

The full lecture, with text and slides are available through this link:
https://davidhealy.org/sex-and-evidence-based-medicine/

Post SSRI Sexual Dysfunction (PSSD) is one of a number of enduring sexual dysfunction syndromes that include Persistent Genital Arousal Disorder (PGAD), Post Finasteride Syndrome (PFS) and Post Retinoid Sexual Dysfunction (PRSD). These states are triggered by treatment and will endure for decades after treatment stops in most cases.

Enduring sexual dysfunction does not convey the horror of the conditions, which typically produce numb genitals, an inability to orgasm, a profound loss of libido and a more general emotional disconnection or anhedonia.

In the case of PGAD, women faced with the opposite problem of irritable or painful genitals resort to having the nerves to their pudendal area cut or to clitoridectomy to manage the discomfort. None of these options help.

There are no cures for these conditions. The distress is great. There are no remedies for the distress. Medical services do not recognize the conditions, even though as of 2020 drug labels do, and healthcare staff routinely ridicule patients adding to the distress. Aware that there are no cures and no prospects of a cure, some patients commit suicide (details available on request). Others explore the possibility of medically assisted dying (details available on request).

Pharmaceutical companies have known about the risks for decades. Regulators had reports of these conditions in the mid-1980s. Neither warned the public or doctors. As a result, hundreds of thousands have ended up taking antidepressants, isotretinoin (for acne) and finasteride (for hair loss) who in many instances did not need these treatments and might not have opted to take them if decently informed.

At present there are approaching 100 Canadians with known PSSD and over 700 with known PGAD and a further cohort of people with either PFS or PRSD.

This is a significant underestimate of the numbers who likely have these conditions but don't yet know about them. PSSD and PGAD typically declare themselves when patients stop treatment and on-treatment sexual dysfunction continues and often gets worse.

Roughly 15% of Canadians take antidepressants (5 million people), a majority of whom do so because they cannot stop (c 3 million). If they could stop, many would expect the sexual dysfunction caused by being on treatment to improve but just the opposite is likely to happen for some people.

MAiD and Enduring Sexual Dysfunction Syndromes 1

The Enduring Sexual Dysfunction Syndromes are serious and incurable physical illnesses.

They are not mental disorders. They are the physical consequences of treatments some of which are given for mental disorders and others for physical conditions.

The distress they cause appears to be as intense as is the distress caused by conditions that have hitherto led people to seek out MAiD when death is reasonably foreseeable.

There are at present no prospects of a cure for these conditions or for relief from distress. Well-intentioned efforts to help are likely to compound the problems and sap rather than support the resilience of those affected.

MAiD and Enduring Sexual Dysfunction Syndromes 2

In addition to concerns about poor services that might push people toward MAiD, the Enduring Sexual Dysfunction Syndromes suggest another factor should be considered.

These illnesses result in part because the medical literature on on-patent drugs is ghost-written and there is no access to the data from healthy volunteer and clinical trials that were undertaken to bring these drugs on the market.

Access to the trial and related data might have made these hazards clear and made for different conversations between doctors and patients.

The distress patients with Enduring Sexual Dysfunctions experience stems not just from ridicule at the hands of healthcare personnel but from a profound sense of being deceived. This sense of being deceived underpins a perception that our institutions have no incentive to find a remedy. For pharmaceutical companies to research the problems would require an

admission their treatments and practices cause the problem. Tobacco and recent finasteride litigations have shown they are unwilling to do this.

Senator Kutcher was an ‘author’ on a famous study of paroxetine given to children commonly referred to as Study 329. The paper was ghostwritten. It is unlikely he has had access to the trial data other than the patients he himself entered into the study. Study 329 led New York State to file a fraud action against GlaxoSmithKline, the makers of paroxetine. Based on Study 329, the US Department of Justice later took an action against GlaxoSmithKline that in 2012 resulted in the then largest sum handed over to resolve a corporate case of this kind - $3 Billion (USD).

The process of ghostwriting articles and sequestering clinical trial data began in earnest a little over 30 years ago. Since then, the time between doctors becoming aware of and generally accepting that the treatments they use come with specific hazards has increased from roughly a year or two to several decades. For PSSD, PGAD and related conditions this interval between first description and recognition is now three decades and counting.

Canadian patients with Enduring Sexual Dysfunctions are certain to seek MAiD because of the distress occasioned by their condition. They have been put in this position by practices that prioritize commercial considerations over scientific, moral, or clinical considerations.

When considering MAiD for PSSD if this is the patient’s wish, perhaps doctors should be willing to support death by hunger strike outside the headquarters of the company making the drug that caused the condition, or the university/hospital that condones practices like those Senator Kutcher engaged in.

David Healy MD **February 17th 2021**.