

This is the 1st affidavit of Elayne Shapray in this case and it was made on _____Aug 2011

No. S112688 Vancouver Registry

IN THE SUPREME COURT OF BRITISH COLUMBIA

BETWEEN:

LEE CARTER, HOLLIS JOHNSON, DR. WILLIAM SHOICHET and THE BRITISH COLUMBIA CIVIL LIBERTIES ASSOCIATION

PLAINTIFFS

AND:

ATTORNEY GENERAL OF CANADA

DEFENDANT

AND:

ATTORNEY GENERAL OF BRITISH COLUMBIA

INTERVENOR

AFFIDAVIT

- I, ELAYNE SHAPRAY, housewife, of 1596 W. 14th Avenue, in the City of Vancouver, Province of British Columbia, SWEAR (OR AFFIRM) THAT:
- 1. I have personal knowledge of the facts and matters hereinafter deposed to, save and except where same are stated to be made on information and belief, and where so stated, I verily believe them to be true.
- 2. I am presently 64 years of age. I was born on September 30, 1946.
- 3. I obtained a nursing diploma from the Jewish General Hospital in Montreal, Quebec in 1967. I have subsequently worked as a nurse on a child psychiatry ward and as a nurse in a paediatrician's office.

- 4. I am married. My husband is a member of the British Columbia bar. I am a mother of two adult children and a grandmother of four grandchildren.
- 5. I have volunteered for many community organizations in a variety of positions including as an intake worker at Family Services of Greater Vancouver, 15 years at the University of British Columbia Women's Resource Centre and approximately 15 years as a palliative care volunteer at the Vancouver General Hospital.
- 6. I have had the opportunity during my 15 years as a palliative care volunteer to be present with many people who were terminally ill. While some deaths were peaceful and calm, too many were, as I observed, excruciatingly heartbreaking, torturous to the patient and for their friends and family who watched their loved ones, cold and clammy and rasping for breath, beg for an end to their own suffering even though their pain was controlled.
- 7. I have multiple sclerosis ("MS"). I make this affidavit in order to assist the court to understand not only how MS affects my life today and will likely affect my life in the future but also to explain how the current state of the law that prohibits physician-assisted dying presently diminishes the quality of my life on a daily basis.
- 8. I was definitively diagnosed with relapsing remitting MS in approximately 1984, however in retrospect, I probably had the disease much earlier. Since that time, my MS has progressed from relapsing remitting to secondary progressive MS. I have consulted with and have been followed by some of the leading professionals in the field of MS about my disease. I have also been to the Mayo Clinic where I sought advice on any potential treatment for my MS. The physicians at the Mayo Clinic confirmed what my BC physicians had told me, namely that there was not any treatment that they could offer me to slow the progression of my disease.
- 9. Through my discussions with my physicians and my own research, I have come to have an understanding of how MS progresses as a disease. MS is not a terminal disease but rather is an interminable disease. MS is an incurable, unpredictable and progressive illness. The most common manifestations of the disease are a combination of fatigue, mobility and balance problems, weakening of the limbs to the point they become spastic and non functional, loss of bowel and bladder control, pain, cognitive dysfunction and depression, speech and breathing

difficulties. Each person's course of the disease is different. While MS does not itself cause death the possible outcome for someone with progressive MS can be total paralysis as well as the inability to eat or speak.

- 10. For many years my disease did not impact severely on my daily life. However, since approximately five years ago, the quality of my daily life and my ability to live independently have been severely compromised. Approximately five years ago I realized that I could no longer manage to live in my house because I could not manage the stairs and I was at severe risk of falling at any time. My husband and I moved to an apartment.
- 11. My condition has deteriorated rather quickly in the past four years. I am presently confined to a wheelchair. I am unable to properly use my left leg and my ability to use my left hand is rapidly deteriorating. I presently require full-time assistance to help me with the activities of daily living including preparing my food, dressing and bathing and transferring from my wheelchair. It is very difficult for me to find comfort in any position for any period of time whether during the day or the night when I should be sleeping. Simple tasks are a struggle and exhaust me. I cannot walk up or down even a single stair without two people assisting me and without going through extreme stress, anxiety and exhaustion. Even the simple act of getting into bed is an exhausting ordeal and requires assistance. Getting out of bed is even more difficult. Turning over in bed is a similar ordeal. I live with constant fatigue.
- 12. These severe disabilities impact on my life in numerous ways. My disease severely compromises my autonomy, my independence, my privacy and my self-esteem.
- 13. My ability to go places and do things with my family presently is seriously restricted by my fatigue, the physical barriers that people without disabilities would be unaware of and my constant need to be proximate to an accessible bathroom. Nor can I devote myself to my grandchildren in the manner that my peers who do not suffer from my disease do as a matter of course. I have an 86-year-old mother who lives in Montreal. I am deprived of the opportunity or ability to visit her or care for her if and when she is ill. I am essentially a prisoner in my own body, sentenced by my disease to spend the rest of my life either in an uncomfortable chair or an equally uncomfortable bed, dependant upon an attendant to answer my calls for assistance.

- 14. While my quality of life today has been severely compromised, I am not contemplating ending my life at this time. However, in addition, my life is further compromised on a daily basis by the terrifying fears that the current state of Canadian law will deprive me of the possibility of a physician-assisted death if and when I should become desirous of that service as a means to end my suffering.
- 15. This is not an abstract concern. The idea that if I wait too long to be able to end my own life, I will be unable to do so if and when I wish to, is a stressful, anxiety-provoking thought that I live with daily. It constantly and dramatically affects my ability to actually and fully enjoy whatever quality of life I am able to achieve now or will be able to achieve in the future.
- 16. I understand that suicide is no longer a crime in Canada. The irony of the current situation as I experience it is that an able-bodied person can commit suicide in a lawful manner but somebody such as myself, who is unable by reason of their disability to do so, cannot. The means available to me to terminate my life unassisted at this time, if I was so inclined, are extremely limited and would likely involve violent, painful or personally terrifying outcomes. I consider the option of taking my own life by conventional "suicide" means, assuming that I was otherwise physically and emotionally able to do so, not only to be dangerous and inhumane, but also likely to be extremely traumatic to my family and my friends.
- 17. I live in dread of the day when I will have been robbed of all meaningful quality of life by the progression of my disease. I fear that I will not have the option that others have of ending ones' own life. I wish to have the choice of a dignified, physician-assisted termination of my life at the time of my choosing rather than being terrified daily about how I may end up simply because at a future date there would be no one able to legally help me.
- 18. The current state of the law deprives me of the freedom to choose how and when I would end my life. The current law may cause me to initiate a premature termination of my life simply because if I wait until I am ready to do so, I may be unable to do so, in any humane fashion, without asking my loved ones to put themselves at legal risk.
- 19. I have discussed my views with members of my family, my closest friends, my rabbi, and physicians whose integrity and professionalism I respect. All of them indicated to me that they

would support my right to have the choice of when to end my life in a dignified manner that is not traumatic for others, such as a violent suicide, as long as I am able to give an informed consent. None of these persons has attempted to influence me to exercise that choice one way or

the other.

20. I also understand that the historical justification of restrictions on consensual, physician-assisted suicide is to protect persons who are vulnerable to undue influence or manipulation. I have many friends in the medical community and I cannot imagine that a qualified physician would be willing to be a party to assisting the death of someone who did not choose assisted suicide of their own free and voluntary will. I, myself, have absolutely no fear or

concerns that I would not be able to make a decision for myself of my own free choice.

21. I wish to address the issue of whether the ability to obtain physician directed palliative pain relief is relevant to my situation. It is not. While MS can cause extreme pain, conventional pain treatment that might be provided to mitigate pain in end-of-life care for sufferers of other diseases such as cancers or ALS may be inapplicable to MS victims whose natural end of life may be years away but whose suffering due to a variety of symptoms continues every day. The suffering I and others with progressive, degenerative illnesses such as MS endure, is both psychological and social, involving a loss of autonomy, independence, privacy and ability to do

the things that give joy to ones life. These losses cannot be meaningfully addressed by any form

of palliative care.

22. The only way to mitigate the suffering that I, as an MS victim, will continue to experience and have attempted to convey in the words of this affidavit is to grant me the assurance that I will one day have the option to request that a physician lawfully assist me to exercise an autonomous choice I may wish to make with respect to my own existence.

SWORN (OR AFFIRMED) BEFORE ME

at Vancouver British Columbia, on

Aug 2011

A Commissioner for taking Affidavits for

British Columbia.

HOWARD SHAPRAY, Q.C.
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BARRISTERS & SOLICITORS
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