IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV 2015-485-235

UNDER	**The Declaratory Judgments Act 1908 and the New Zealand Bill Of Rights Act 1990**
BETWEEN	**LECRETIA SEALES**
	Plaintiff
AND	**ATTORNEY-GENERAL**
	Defendant

AFFIDAVIT OF DR HICKEY FILED ON BEHALF OF THE CARE ALLIANCE

Sworn 8 May 2015

Next event date: For hearing 25 May 2015
Judicial officer: Justice Collins

Counsel: Victoria Casey
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McLeod and Associates
Auckland
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I, Huhana Susan Jane Hickey, of Auckland, Research Fellow at AUT University, affirm:

Qualifications and Experience

1. I am presently employed as a Research Fellow at Taupua Waiora Centre for Maori Health Research, National Institute for Public Health & Mental Health Research, at AUT University in Auckland. My previous roles have included:

    1.1. Senior Lecturer, School of Inter-professional Health, AUT University

    1.2. Solicitor, Auckland Disability Law

    1.3. Co-Director, The Advocate, KFM Associates Limited, Christchurch

    1.4. Lead Investigator, Maori Development Research Centre, Hamilton

2. In 2008 I was awarded PhD in Philosophy by the University of Waikato. My doctoral thesis (The Unmet Legal, Social and Cultural Needs of Maori with Disabilities) was supervised by Professors Margaret Bedggood and Ngahuia Te Awekotuku. I graduated LLM with Distinction (2001) and LLb/BSocSci (1999) from the University of Waikato. In 2004 I was admitted as a barrister and solicitor of the High Court of New Zealand.

3. I have been active in many community groups and official committees over the past two decades, including:

    3.1. Founding member, Not Dead Yet Aotearoa

    3.2. Board member, Community Law Centers of Aotearoa

    3.3. Chairperson, Auckland Council Disability Leadership Group

    3.4. Panel member, Human Rights Review Tribunal, Ministry of Justice

    3.5. Council member, Muscular Dystrophy Association of New Zealand

    3.6. Council member, Te Roopu Waiora Trust

    3.7. Founder and President of the Mana Tuaakiri branch of the Maori Women's Welfare League

3.8. Indigenous People's Representative, United Nations International Steering Committee

3.9. Maori Representative, CCS Waikato

3.10. Advisor, Ministry of Health Northern Y Ethics Committee, Waikato

3.11. Member, Steering Committee for the establishment of People First New Zealand

3.12. Foundation member, Health and Disability Commission Advisory Group, New Zealand

3.13. President, Workbridge Council

3.14. Committee member, Special Needs Education Research Group, Ministry of Health

3.15. National Advisor on the NEC, Disabled Persons Assembly

3.16. Board member and Life member, Rostrevor House

4. My awards, grants and scholarships include:

4.1. Member of the New Zealand Order of Merit (2015)

4.2. HRC Grant (2015)

4.3. Te Amorangi Maori Excellence Awards (2009)

4.4. Maori Excellence Award, School of Maori and Pacific Development, Waikato Univeristy (2006)

4.5. Recipient of the VCC Waikato University Phd Scholarship (2003-6)

4.6. Rosemary Seymour Women's Studies Maori Women's Award (2001)

I am directly affected by this claim

5. I am a founding member of Not Dead Yet Aotearoa (NDYA) which is a group of disabled people who oppose the legalisation of euthanasia and assisted suicide. NDYA is a member of the Care Alliance, and linked to other disability advocacy groups internationally.

6. I am directly affected by Ms Seales' claim. Her claim, as I understand it, is that it is right and rational to describe the following circumstances as "unendurable", "intolerable" and "lacking in dignity":

    6.1. loss of mental faculties;

    6.2. total dependence on others, including as to daily hygiene activities;

    6.3. intense pain;

    6.4. loss of memory;

    6.5. seizures;

    6.6. personality and behavioural changes; and

    6.7. loss of mobility.

7. As I understand it, Ms Seales' claim is that the Court should approve that it is rational for people in such circumstances to commit suicide. More than that, that State should authorise other people to help them do it.

8. I have primary progressive multiple sclerosis (MS). This means that I face constant pain and periodic seizures, which can be addressed with drugs such as morphine, codeine, tramadol, garbonten and paracetomol. Unfortunately the side effects of such drugs can temporarily affect my ability to concentrate, focus and remember.

9. There is no cure for MS, and my variant never goes into remission. I can expect it to become progressively worse.

10. I rely on others for much of my personal care, including daily hygiene activities. I use a powered wheel chair. There is no loss of personal dignity in receiving such assistance. My partner, family, friends and caregivers treat me

with the utmost respect and love at all times.

11. I am fortunate that my employer is supportive of my circumstances, but I know that is not the norm for many people with significant disabilities.

12. I have had many challenges in my life, starting with being born one month premature to my unwed 16-year old mother. She was advised to leave me in hospital shortly after giving birth because I was an "imbecile" and "idiot" and that I was unlikely to survive. I was later adopted by a married couple who had been told "a little white girl" was available for adoption, even though my whakapapa is actually Maori, Aborigine and Native American.

13. My adoptive parents, my father in particular was kind, loving and generous. I had many health problems as a child, particularly with my breathing, and was eventually diagnosed as asthmatic at age 18.

14. Although I showed musical ability from an early age, I was regarded as slow and stupid by teachers. I developed self-destructive behaviours and attempted suicide. I became pregnant at a young age and gave birth to my first son in 1980. I was forced to give him up for adoption.

15. In 1986 I gave birth to my second son. While it was a difficult labour for myself and my baby, it marked a turning a point in my life. I made a commitment to be his mum and to care for him.

16. I had begun training as a nurse when I was 17-years old, but I had not completed the training. I returned to the training in 1991, but by then was in constant pain and began to rely on walking aids. I underwent numerous investigations and eight operations, but without a firm diagnosis or improvement. It was only in 2010 that I received a diagnosis of primary progressive MS, which is a relatively rare form of the disease. I was not able to complete my training as a nurse, as I was not considered to be physically capable of performing the work.

17. In 1993 I enrolled at the University of Waikato for a degree in psychology. I found that I enjoyed the courses and, to my surprise, that I was good at it, earning three As and two Bs in my first year. I subsequently completed a conjoint degree in Psychology and Law, before completing postgraduate

degrees.

18. During my early studies at university I was in a violent domestic relationship. One beating left me with a head injury, which compounded my other health issues. I later had to make a complaint to the Human Rights Commission before the Waikato District Law Society would issue me with a practising certificate as they had determined that I had brain damage that precluded me from practising law safely.

19. Due to my personal circumstances I have developed a strong interest in advocating for disabled people's rights. Fundamental to such advocacy is the importance of disabled people speaking for themselves, rather than being mediated through some officially-approved spokesperson who may or may not understand our deepest perspectives. We refuse to be classified as "patients", as if our health needs define our personalities, capabilities and worth. We are simply people.

20. Similarly, I refuse to accept that my physical challenges can or should be perceived by anyone as being "unendurable" or "intolerable". I will not accept anybody's pity, but I deeply appreciate their help. This is my one life, and I am determined to approach it with an attitude that embraces all the joys and challenges combined.

21. Each of us chooses our response to the challenges given to us. Five years ago I became a Buddhist, in part because the meditation practises help to centre me during the difficult times, of which there are many. All of my experiences have made me stronger and more capable: for example, I now know that depressive episodes can be managed effectively, and that it will pass with the right medications and practices, and patience.

Euthanasia and assisted suicide devalues disabled people

22. At the heart of arguments for euthanasia and assisted suicide is a belief that some lives are not worth living. That attitude devalues the lives of disabled people.

23. It is an attitude that is reinforced daily by the media's idealisation of what constitutes a 'good life': the perfect body, a better house in a better suburb, a

high-paying high-status job, the accumulation of material goods or exciting experiences. Meanwhile, disabled people face up to accomplishing the every day tasks that others take for granted: washing, getting dressed and fed, having the dignity of work. We truly know that "the perfect is the enemy of the good".

24. Disabled people are at higher risk of depression and suicidal ideation simply because our daily lives are harder than the population as a whole. Part of the answer, as with the general population, is to improve access to the anti-depressive treatments and supports that are available, and to overcome the prejudices around asking for help for mental illness. A bigger part of the answer, for disabled people, is to make our daily lives just a little bit better: not just physically but also, perhaps more importantly, socially.

25. Being accepted as equal participants in society is our goal and our right. While much progress has been made in recent years through legislation, policies, programmes and education initiatives, it is fragile and uneven progress. Disabled people are still subject to ignorance and prejudice. A judicial declaration that a life which includes interdependence with others, restricted mobility, chronic pain and "personality and behavioural changes" is not worth living would go directly against all the progress that has been made. It would be worse than that because even in the darkest times of our history as disabled people in New Zealand, New Zealand never actually put into law the statement that we were better off dead.

26. The disabled must have equal rights to suicide prevention: if a supposedly well or non-disabled person commits suicide, there is generally shock and horror as people examine the environmental causes that may have led them to suicide. However, when sick and disabled people show a desire to wish to commit suicide, assisted or unassisted, suddenly what is normally perceived as an irrational non-starter caused by depression is reframed as a brave and courageous rational decision because of their circumstances. There is an unspoken assumption that they would be better off dead. Allowing Ms Seales' claim would confirm that assumption and enshrine it into law.

27. The legalisation of euthanasia and assisted suicide would inevitably inhibit the provision of better services for the disabled. We already live with a degree of

'looking away' by some of our fellow citizens, perhaps because they do not want to imagine what it would be like to have to live as we do. This can extend to subtle discrimination by those we most rely on: for example, some doctors, nurses and carers can make unconscious distinctions about the types of treatment and care that should be considered.

28. Health and welfare services for the disabled have to be funded from the limited resources available to meet the health and welfare needs of all New Zealanders. Legalising euthanasia and assisted suicide in 2015 needs to be assessed for its long-term impacts on future resource allocation decisions. For example, what would happen if New Zealand's economy took a turn for the worse, putting pressure on the government's budgetary priorities? Would a future government decide that funding services for the disabled and elderly was a lower priority because there was a cheaper, judicially-endorsed alternative "treatment" available?

I Am Deeply Frightened

29. I am therefore deeply frightened, for myself and other disabled people, that the act of declaring that *some* lives are not worth living will legitimise a belief that *my* life is not worth living.

30. I am aware that in some countries with legalised euthanasia and assisted suicide that people with dementia have been killed without their consent. This is the logical extension of a belief that some lives are not worth living, made by "well-intentioned" people making decisions on behalf of people who are deemed unable to think or speak for themselves.

31. The infamous 2013 case of the killing in Belgium of twins who were deaf and losing their sight is further chilling evidence that an idea that starts with compassion can readily lead directly to the killing of people with disabilities *because of* their disabilities.

32. I can expect that my disease will progress to the stage that I will be bed-ridden for long periods. I will be totally reliant on others for my physical well-being, and I may be unable to speak clearly or communicate well. That is a real prospect of intense vulnerability. I am afraid of the decisions that will be made about my care if the law sees my life as having no value, and

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sees my premature death as a rational response to my situation.

Thinking About Dying

33. I have been privileged to have been able to journey with family and friends to the end of their lives. It is my experience that the able-bodied often respond to the first news of approaching death by naturally proceeding through the classic Kubler-Ross stages of grief: denial, anger, bargaining, depression, and acceptance. By contrast, many disabled people have already passed through the early stages because they long ago came to terms with the vagaries of life's wheel of fortune.

34. When I was a young trainee nurse at Waipukurau Hospital, the Matron asked me to help her prepare the body of a patient who had just died. I was young and inexperienced and frightened, but she showed me how to attend to the body with great care and dignity, cleaning death's usual fluids and discharges with tenderness and respect. That experience has stayed with me ever since. It taught me that we need honest conversations about death and dying. We must not treat it as one final commodity to be packaged into an antiseptic experience and hidden from sight.

Affirmed at Wellington)
this 8th day of May 2015)
before me:)

Fiona Miller

A Solicitor of the High Court of New Zealand

Fiona Lindsey Miller
Solicitor
Wellington