# 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 LECRETIA SEALES SWORN 9 APRIL 2015

# I, LECRETIA SEALES, of Wellington, lawyer, swear:

- 1. I am the plaintiff in this matter.
- I am a lawyer employed as a senior legal and policy adviser with the Law Commission. I have been on unpaid leave since 18 March 2015 so that I can focus on my court case and receive intravenous chemotherapy at Wellington Hospital. Prior to working at the Law Commission I worked for law firms Kensington Swan and Chen Palmer. My area of expertise has been public and administrative law.
- I have just turned 42 and live with my husband Matt Vickers and our Abyssinian cat, Ferdinand, in Wellington. I met my husband Matt in 2003.
   We got married in 2006. Matt and I have a close and loving relationship and he is an incredible support to me. We were unable to have children.

## My background

- I was born and grew up in Tauranga. I am the eldest of three children. I
  have a younger brother and younger sister. Both currently live in
  Auckland. My parents continue to live in Tauranga.
- I had a happy childhood and remain close to my parents and my siblings.
- 6. I have always been a fiercely independent and driven person. I did very well at school academically and was also involved in a wide range of other activities. I was particularly interested in dance and took up ballet at a young age. I also learned jazz ballet and then tap dance. I have continued to be passionate about dance ever since. I have participated in a number of sports including competitive roller skating (similar to ice skating) and hockey. I also took part in speech and drama lessons which I continued with until university (where I gained ATCL speech and drama and taught children).
- 7. From a young age i was passionate about cooking and I would prepare meals for my family on special occasions or bake cakes from as early as the age of eight or nine. I remember when I was about nine making a baked Alaska from scratch and without adult help. My passion for cooking has continued throughout my life.
- 8. I worked hard at school but I was organised so I also had time to socialise and spent plenty of time with friends, going to parties and the beach as teenagers do. I was also a very self-conscious girl growing up, and was easily embarrassed if I stood out in any way.
- 9. I was determined to be as independent as possible from my parents once I went to university so I worked hard in various jobs during my last two years at school, saving money for when I left home. My father said he would match me one dollar for every dollar that I saved, but I don't think he expected me to save as much as I did. I had a number of jobs, including working in a French bakery, at a superette and at a pie cart, from midnight to 5 am on the weekends.
- 10. When I finished my seventh form year I left home to study law in Wellington where I knew no-one. I continued to work part time in various jobs as well as working hard on my studies and continuing with a range of other activities including dance.



- 11. After I graduated, I worked at Kensington Swan for three and a half years. I paid off my student loan by choosing to pay back additional amounts from my salary, and then went backpacking around Europe with a girlfriend for three months.
- 12. For the next two years I worked in London in various legal roles. During that time I travelled extensively and made the most of the culture on offer. I particularly enjoyed restaurants, cooking courses, and attending the ballet and theatre.
- 13. In 2002 I returned to New Zealand as my mother was unwell and my family dog was dying. I took a job at Chen Palmer and in 2007 moved to the Law Commission where I have worked ever since, albeit on a part time basis since I became sick.
- 14. I consider myself to be very independent and determined. I am also a private person. I have always been reserved about my personal life. It is a joke amongst my closest friends that I am hard to get information out of. In addition to valuing my privacy, it is very important to me to present myself in a measured and composed way, no matter what the situation.
- 15. I have been lucky enough to be born with a good brain and this has been an enormous feature in my life. I have been fortunate never to have suffered from depression or to have felt unable to pursue the things that matter to me in life.
- 16. I get great enjoyment out of my work and have been lucky with the profession I chose. I have worked with many great legal minds and have been involved in a range of law committees and organisations because of my passion in this area. I have been greatly enriched by my career which has engaged and challenged me so much and which I continue to enjoy.
- 17. I have always had a number of interests and passions including hosting dinner parties, cooking, dancing (tango), and learning languages (German, Spanish, Italian and Māori). I have been an avid reader.
- 18. In addition to my relationship with Matt, I have a very close relationship to my parents, Shirley and Larry Seales, and my brother and sister. I talk with my mother on the phone every few days, and for at least an hour on Saturdays. I have done so since I left home. I am very close to my numerous aunties and uncles. As a first grandchild, I was a focus for many of them and often spent school holidays with them. I also have a wide range of close friends, some going back to primary school. I have tended to retain the friends I have made through work or socially over the years. I think this is because of the importance I place on friendships and the efforts I make to stay in touch, even when friends live abroad.

# My diagnosis

- 19. I was diagnosed with brain cancer in 2011. In 2010 I began experiencing headaches and some loss of vision on my left side. At the time I was working long hours on secondment from the Law Commission at the Department of Prime Minister and Cabinet ("DPMC"). An optometrist I consulted at the time put my symptoms down to tiredness and overwork. I also thought that I might be suffering from migraines.
- 20. Around that time, I remember driving home from a cake decorating course at Newlands College when I hit a dark coloured car parked on the

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- left. A person from a neighbouring house came out and told me that it had happened before on the same bend so at the time I thought it was a question of inattention and bad luck.
- In late 2010 my headaches were becoming constant and more severe. I returned from my secondment at DPMC to the Law Commission. In early 2011 I visited my GP, about my headaches and referred me to a neurologist. advised me to make a private appointment because of the long waiting lists in the public system which I did (I had health insurance). I still had to wait three months before the first appointment with the neurologist.
- 22. Around this time Matt and I were making arrangements to go to San Diego for fertility treatment, plans that were made following a number of unsuccessful rounds of IVF.
- 23. When I saw the neurologist specialist in March 2011, I was immediately referred for an MRI because of his concerns about the nature of my visual problems. I was diagnosed with a brain tumour pretty much immediately after that. After surgery and pathology tests, I was told the type of brain tumour was oligoastrocytoma grade 2 combined with the less aggressive oligodendroglioma.
- 24. I was told that the tumour was diffuse with tentacles reaching all through my brain and that it would not be possible to surgically remove it. I was also told that the tumour was pressing on my spinal column and that there was a risk I could go into a coma and die within the next few weeks. Indeed if I had travelled to San Diego as planned and put back the appointment this may have happened. Because of this immediate risk I underwent urgent surgery to remove some of the tumour and relieve the pressure.
- 25. I remember going into that surgery was a terrifying experience. It was unclear whether the surgery would be successful, or I would die, or there would be damage caused to the brain which could cause blindness, paralysis or other disability. Nevertheless, I remained optimistic and resolved to get through it. It was a devastating diagnosis but I was determined not to fall apart, and to maintain the dignity and independence that is so central to who I am.
- 26. The surgery went as well as it could, which was a great outcome. As I was recovering at home from the surgery I began to absorb the full enormity of my diagnosis. But I knew that I did not want this diagnosis to determine or change the person that I am. I did not want pity from others and I did not want self pity to get in the way of what life could continue to offer me. I resolved to live whatever remained of my life as well as I possibly could, focussing on all the things I enjoyed which were my work, cooking, dancing, my husband, my family and my friendships. I knew I wanted to really live while I am still living.
- 27. Following the surgery I underwent six weeks of intensive radiation therapy which left my scalp very burnt. As a result of the burns and scarring my hair has never fully grown back. The radiation successfully shrank the tumour and allayed its growth for a period of time. I continued working but reduced my hours to 30 hours a week. This was because of additional fatigue I suffered following the radiation. The difficulties with my eyesight also made reading very tiring because of the concentration required. With the slightly reduced hours I was nevertheless able to

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continue to work to my usual high standards and get great enjoyment out of the projects I worked on.

- 28. In 2013 I travelled to Argentina with my husband and my parents. I had chosen Argentina because I am passionate about dance and the tango in particular. I wanted to dance the tango in Buenos Aires. Matt and I had been having dancing lessons to learn the tango for this purpose. Around this time it became apparent that the tumour was beginning to grow again. While I was away I started to experience more paralysis on the left side of my body. I had difficulty holding a cup and my walking became more difficult. When I came back from the holiday these symptoms worsened and I began to use a walking stick.
- 29. My treatment options were becoming more limited. I could not undergo any further radiation therapy. Matt had read about a chemotherapy drug called Temozolomide which is available in the UK and in Australia and can be very effective in treating brain cancer. However, this drug was not funded in New Zealand for grade 2 tumours like mine, and cost about \$700 a week. My husband and I paid for the first month's supply. My mother then tracked down an old friend who worked in the pharmaceutical industry in the hope of finding a cheaper pharmacist. The contact connected her with an executive at Merck, which had lost the Pharmac tender for Temozolomide and had a store of the expensive drug sitting in its warehouse going to waste. The company agreed on compassionate grounds to let me and several other patients have it for free.
- 30. This treatment worked very well for me from May 2013 until August 2014. My symptoms lessened, although I had some remaining loss of movement on my left side. I continued to enjoy my work and other interests. I went to San Francisco with Matt and then to Bermuda to visit an old school friend.
- 31. From around August 2014 the chemotherapy was stopped on my doctor's advice following a scan that possibly indicated it was no longer working. From August / September 2014 I gradually started to experience symptoms that indicated the tumour was growing, particularly increased paralysis down the left side of my body and headaches.
- 32. Despite this set back, I resolved to continue to live my life as best I could, and in October last year travelled to Morocco with my parents and Matt. My mobility was becoming increasingly difficult at this time and I had to be helped up and down any flights of stairs by Matt and my father. I was not going to let these difficulties stop me from getting the best out of my life.

# **Current position**

33. Since October last year, my condition has continued to deteriorate. The paralysis is gradually increasing on the left side of my body. My left arm and leg and hand no longer work properly and I can't see anything left of centre. I have been prohibited from driving for several years. Walking is becoming increasingly difficult even with a walking stick. My left foot is useless and has to be lifted to get into a car or moved into position when I am standing up from a chair. Unless I am sitting in a chair of the correct height! have to be helped to stand.

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- 34. I can no longer dress or undress myself without help. Matt helps me. If he is away for work and my mother or other friends stay, they help me. I need help with putting on my bra and getting clothes over my head and my left arm into sleeves. I need a rail for using the toilet to be able to balance myself and we have had our bathroom adapted so that I am able to use the shower independently. One of my greatest passions is cooking which I can no longer do because I no longer have strength in my left hand.
- 35. More recently I have found I have difficulty swallowing when I am drinking liquid and tend to choke. I have headaches most days which can be quite painful but currently can be treated with painkillers. I also have shooting pain in my left buttock that can be quite severe which I understand is pain related to the tumour. I can still read and have been able to continue to work through my determination but the reading is tiring because of the concentration needed given my poor vision. I can no longer read for enjoyment.
- 36. I have been having an increasing number of falls because of the paralysis on the left side of my body and the visual impairment, which interferes with my balance. If I fall I cannot get up again by myself. I manage this by being careful not to bend over and pick something up and to take extra care when I am standing up and sitting down when I am on my own. In addition to the alterations made to my home bathroom, arrangements were made at the Law Commission for a toilet rail for me to use. For me, the discussions around this requirement were mortifying and so a work colleague (and friend) advocated on my behalf.
- 37. My illness is impacting on my ability to do lots of things including performing basic household tasks and my personal tasks, and I do find the lack of independence, and the impact on my dignity and privacy, increasingly difficult.
- 38. My oncologist, has advised me that further treatment cannot cure the tumour, although it may temporarily halt or slow progression of the tumour, and that the tumour will prove fatal. I am advised that I could live for between 3 and 18 months, although it is difficult to predict the behaviour of tumours.
- 39. I am currently investigating other treatments that I understand are less likely to be effective and carry increased risk. I have started intravenous chemotherapy and will continue this as long as it makes a difference and/or if my immunity and blood count allows it. I understand that there are diminishing returns with this type of treatment.
- 40. Although the symptoms are difficult and I am less independent, I still make the most of every day of my life and remain as independent as I can. I go to the ballet, regularly meet friends for lunch, go on day trips out of Wellington to visit friends and go to restaurants. I have continued to go into work every day at the Law Commission until 18 March when I took leave so I could focus on this case and further treatment.

## Progression of my disease

41. I know there is no certainty about exactly how my illness will progress. I understand it depends on which tentacle goes further fastest. If it compromises a vital bodily function I could die suddenly but I understand

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it is more likely the tumour will slowly grow, resulting in the continuing advancing paralysis on my left side and a range of other symptoms.

- I do not know how my death will be but, given my current condition and likely further symptoms, it could be a difficult, slow and unpleasant one. I want to be able to ask a doctor to help me end my life peacefully if and when it gets to a point where my life is no longer bearable. It is possible that the way my illness progresses will mean that I am able to manage with what help is available and I won't need to seek the help of a physician to die. But I want to have a choice to be able to say enough is enough, if I can no longer bear the suffering and indignity, and to be able to die peacefully with my husband and family around me.
- 43. I fear being totally immobilised and losing control of my bodily functions. I cannot bear the thought of being fully incontinent and being unable to clean myself. I fear not being able to swallow, and feeling like I cannot breathe properly. I am already having trouble swallowing, which leads to choking. It will only get worse.
- I can currently manage the pain from headaches and the pain in my left buttock but I am aware this pain could become more intense. In the past, I have been treated with steroids to manage the headaches. For me the side effects were constant insatiable hunger and an inability to sleep, even with sleeping pills, which I found terrible. I don't want to be in a position where I am given pain killers or sedatives to a level where I am in a drugged haze, not able to communicate with loved ones properly (or at all) nor able to be fully aware of my life and surroundings.
- 45. A possible outcome for my illness is falling into permanent unconsciousness. I hate the thought of slowly dying over days or weeks from lack of food and water while my loved ones stand around and watch that happen. I cannot bear the thought of my parents and husband having to go through that.
- 46. I don't want to be in a situation where every minute of every hour of every day I am wishing that the suffering and indignity could end but I am powerless to do anything. I fear being unable to swallow or speak or move while people around me deal with my excrement and wash me and feed me. I don't want to have to suffer pain or discomfort where the only option is high doses of pain killers or sedatives that leave me hardly present in my own life and / or don't always address the pain. I don't want to live out my final days and weeks in a state where I am drugged to the eyeballs and no longer recognise my husband. I don't want to be virtually unconscious, breathing and that's all.
- 47. For the moment I will continue living my life every day as best I can. Despite my current disabilities and problems I do treasure every day and have no present desire to end my life. I do not lack courage. If my death is manageable I should be the one to manage it. But I cannot rule out that it will be unbearable even with palliative care. Dr acknowledges that, for many of my symptoms, palliative care will have minimal effect. This would include the loss of physical or mental capacity, being unable to swallow and the loss of the ability to communicate. While I understand that pain can usually be managed, there can be no guarantees that pain relief will address all pain. If pain relief is required in high doses, I am concerned that it could impact on my awareness of myself and my loved ones.

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- 48. As my death has become more inevitable, I constantly worry that it could be slow, unpleasant, painful and undignified. I worry that I will be forced to experience a death that is in no way consistent with the person that I am and the way that I have lived my life. I know that it might not turn out this way, but even the chance that it will is weighing on me very heavily.
- 49. Because of this I have started thinking about what I could do to end my own life before I become physically unable. This is not a choice I want to make. I know that if I do take this action I would probably have to do that much earlier than I would if I could ask a doctor to assist me with my death. But my other choice is to face a possibly unbearable death.
- 50. My paralysis means that I am already limited in the methods I could use to end my life. However, there are still means available to me and I feel I have no choice but to consider them. I know that some of these methods might not work (eg poison or carbon monoxide) and could cause my family further suffering. I know that if I take my own life, I will need to do so alone and in secret to avoid the possibility of my loved ones being implicated. I hate the thought of going through that alone, with my loved ones having to find me, and not being able to say goodbye to them properly. If I wait too long to make this decision, I could become physically unable to take my own life other than by refusing food and water. I do not want to die that way but dying that way may still be more bearable than having to suffer through to the bitter end without choice.
- 51. It seems incomprehensible to me that I can exercise a choice to end my life when I am able, and still have quality of life, but can't get any help to do so at a later point when my life no longer has any quality for me. I want to live as long as I can but I want to have a voice in my death and be able to say "enough".
- 52. I am not depressed. I have accepted my terminal illness and manage it in hugely good spirits considering that it's robbing me of a full life. I can deal with that, and deal with the fact that I am going to die, but I can't deal with the thought that I may have to suffer in a way that is unbearable and mortifying for me.
- 53. I have lived my life as a fiercely independent and active person. I have always been very intellectually engaged with the world and my work. For me a slow and undignified death that does not reflect the life that I have led would be a terrible way for my good life to have to end.
- 54. I want to be able to die with a sense of who I am and with a dignity and independence that represents the way I have always lived my life. I desperately want to be respected in my wish not to have to suffer unnecessarily at the end. I really want to be able to say goodbye well.

#### What assisted dying would require

- 55. If it did get to the point where my suffering was intolerable, and if my doctor could assist me legally, I understand that a process would need to be followed to satisfy my doctor that providing me with assistance to die is appropriate in the circumstances if I was to pursue that choice.
- 56. First, I would continue to discuss assisted dying with my doctor over a period of time (to the point where we were both satisfied that was my clear intention).

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- 57. I realise that my doctor would need to be satisfied that I was mentally competent, and that I could make an informed choice. I expect may want to consult with specialists concerning my condition.
- 58. I would need to discuss the alternative options (including palliative care) with my doctor and specialists and consider whether they might provide adequate relief for my symptoms and whether I could live with the other forms of suffering with palliative assistance.
- 59. I would involve my husband Matt and my family in all of those discussions as I have done to date.
- 60. At the end of that process, I could discuss an end of life plan with my doctor to enable me to have a safe death. That would include discussion of the medications to be used and of the appropriate place and time.
- 61. I understand that the process above and the assistance of my doctor would need to meet the requirements of any order made by the Court.

**SWORN** at Tauranga this 9<sup>th</sup> day of April 2015 before me:

A solicitor of the

John Wayne How

Solicitor Thursman High Court of New Zealand

Lecretia Seales